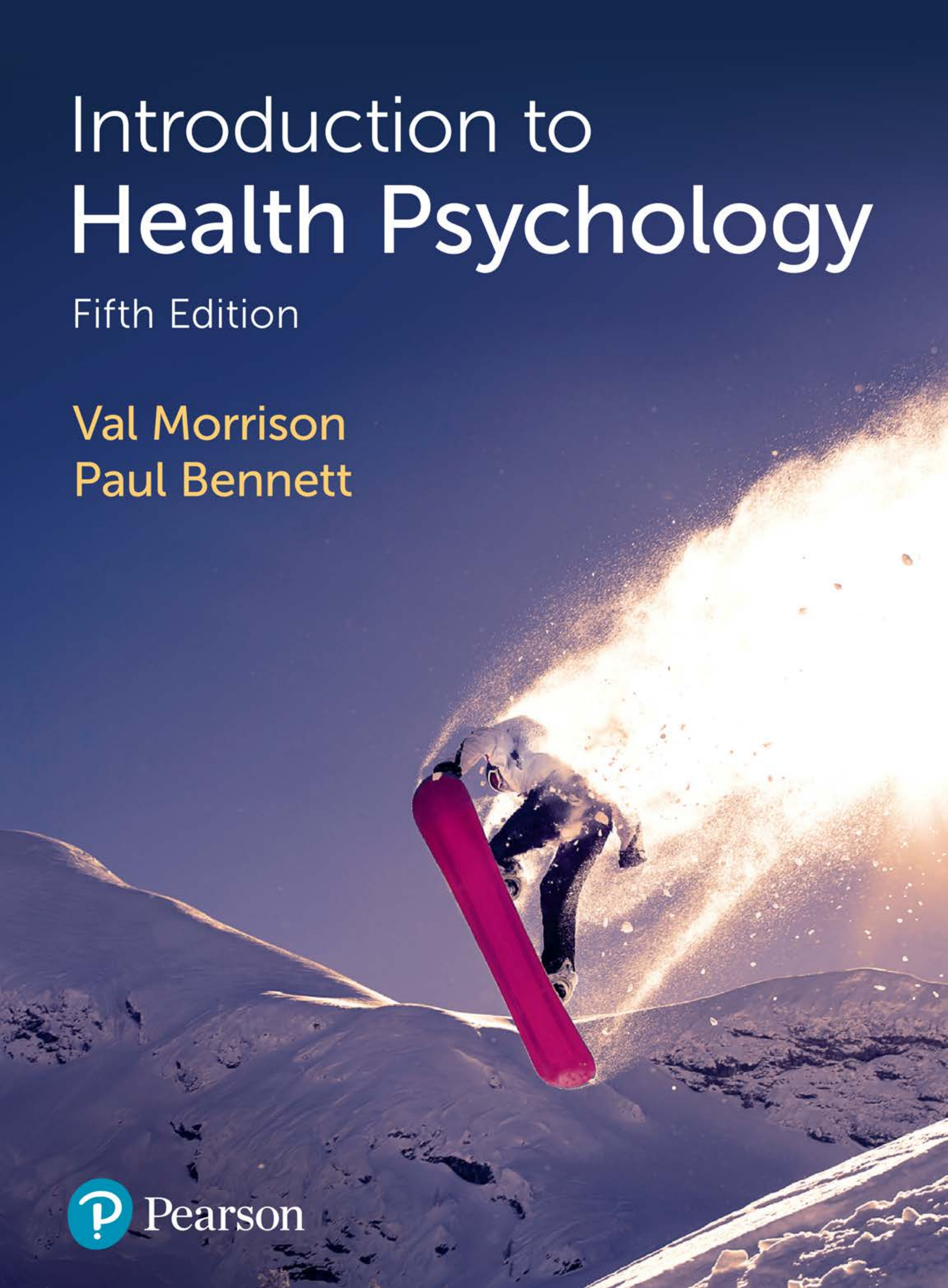

# Introduction to Health Psychology

Fifth Edition

Val Morrison
Paul Bennett

Pearson

# An Introduction to Health Psychology

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# Health Psychology

Fifth edition

**Val Morrison and Paul Bennett**

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First published 2006 (print)
Second edition published 2009 (print)
Third edition published 2012 (print)
Fourth edition published 2016 (print and electronic)
**Fifth edition published 2022 (print and electronic)**

ISBN: 978-1-292-26290-1 (print)
978-1-292-26291-8 (PDF)
978-1-292-26582-7 (ePub)

**British Library Cataloguing-in-Publication Data**
A catalogue record for the print edition is available from the British Library

**Library of Congress Cataloging-in-Publication Data**
Names: Morrison, Val, 1961- author. | Bennett, Paul, 1955- author.
Title: Introduction to health psychology / Valerie Morrison and Paul Bennett.
Description: Fifth edition. | Harlow, England : Pearson Education, 2022. | Includes bibliographical references and index. | Summary: "Well, it's that time again . . . time to bring out another edition of the book. As always, a new edition offers authors an opportunity to update, revise and generally 'improve' the text. This time however the text has faced additional needs for new material in order to reflect the impact of the most challenging health threat to the world experienced in this century: COVID-19. This condition has inspired significant medical developments and has also presented several challenges to health (and clinical) psychologists, to public health professions, and to health practitioners in primary, secondary, and tertiary care across the globe"-- Provided by publisher.
Identifiers: LCCN 2021061221 (print) | LCCN 2021061222 (ebook) | ISBN 9781292262901 (paperback) | ISBN 9781292262918 (epub)
Subjects: LCSH: Clinical health psychology.
Classification: LCC R726.7 .M77 2022 (print) | LCC R726.7 (ebook) | DDC 616.001/9--dc23
LC record available at https://lccn.loc.gov/2021061221
LC ebook record available at https://lccn.loc.gov/2021061222

10 9 8 7 6 5 4 3 2 1
22 21 20 19 18

Cover design: Kelly Miller
Cover image: Martin Steinthaler/Moment/Getty Images

Print edition typeset in 9.75/13 pts and Times LT Pro by Straive
Printed in Slovakia by Neografia

NOTE THAT ANY PAGE CROSS REFERENCES REFER TO THE PRINT EDITION

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# Preface

## Background to this book

Well, it's that time again . . . time to bring out another edition of the book. As always, a new edition offers authors an opportunity to update, revise and generally 'improve' the text. This time however the text has faced additional needs for new material in order to reflect the impact of the most challenging health threat to the world experienced in this century: COVID-19. This condition has inspired significant medical developments and has also presented several challenges to health (and clinical) psychologists, to public health professions, and to health practitioners in primary, secondary, and tertiary care across the globe. Our readership includes students of all these specialties. Questions have ranged from those at a population level e.g. how do we influence the health or safety behaviours of entire populations?, to those at an individual level e.g. What is the psychological impact of the pandemic and how might we meet the psychological needs of people who have experienced COVID-19 or been involved in their care? Each of these, and other, issues are addressed within a book that comes at a time where health psychologists are advising governments and influencing policy and practices perhaps more than ever before – thus it is an exciting time to bring this to you.

Edition 5 of our book is not just an update on previous editions, but has seen a number of significant revisions, reflecting changes in the developing research base, the academic provision of health psychology teaching in university courses, and in the practice of health psychology. We remain true to our original beliefs i.e. we believe health psychology is an exciting and vibrant discipline to study at both undergraduate and postgraduate level. It has developed into an exciting professional discipline with a defined training pathway and increasing numbers of relevant jobs both in healthcare systems and other contexts. We wrote the first edition of the book because we believed that a comprehensive European-focused textbook was required that didn't predominantly focus on health behaviours and illness prevention, but gave equal attention to issues in health differentials, in illness experience, and in healthcare practice and intervention. In addition, we believed that healthcare training textbooks should be led by psychological theory and constructs, as opposed to being led by behaviour or by disease. Diseases may vary clinically, but psychologically speaking, they share many things in common; the potential for life or death, behaviour change, distress and emotional growth, challenges to coping, potential for recovery, involvement in healthcare and involvement with health professionals. We stick to this ideology; as clearly supported by many other people, because we have been asked to produce this fifth edition. Thank you!

We have maintained our comprehensive coverage of health, illness and healthcare, while updating and including reference to significant new studies, refining some sections, restructuring others, and basically working towards making this new edition distinctive and (even) stronger than the last! We believe an understanding of the real-life use of health psychology theory and principles is key to fully understanding its benefits, and as our readership includes many people already involved in (or considering) training for health professional roles we have integrated a lot of experiential qualitative findings and several case studies into the chapters to bring the human and clinical perspective even more to life.

## Aims of this textbook

The overall aim of this textbook is to provide a balanced, informed and comprehensive UK/European textbook with sufficient breadth of material for introductory students, but which also provides sufficient research depth to benefit final year students or those conducting a health psychology project, including at Masters level. In addition to covering mainstream health psychology topics such as health and illness beliefs, health behaviour, and health and illness outcomes, we include key topics such as socio-economic influences on health, biological bases, individual and cultural differences, the impact of illness on family and carers, and psychological interventions in health, illness and healthcare. These are all essential to the study of health psychology.

In this edition, after some deliberation about alternatives, we have stuck to a format in which chapters follow the general principle of issue first, theory second, research evidence third, and finally the application of that theory and, where appropriate, the effectiveness of any intervention. This text is intended to provide comprehensive coverage of the core themes in current health psychology, but it also addresses the fact that many individuals neither stay healthy, nor live with illness, in isolation. As well as significant others being addressed in the chapters relating to influences on dietary or smoking behaviour, or in providing support during times of stress, the focus on the role of family and wider social circle in the illness experience has been one of this textbook's unique features since 2006. Although other mainstream health psychology texts are now better at acknowledging carers and family role in the illness experience, in this 5th edition we continue to devote all of Chapter 15 to this topic.

Another goal of ours was to acknowledge that Western theorists should not assume cross-cultural similarity of health and illness perceptions or behaviours. Our models may not generalize or be upheld when we access research samples more inclusively. Therefore, from the first edition to this current edition we have integrated culturally inclusive examples of theory and research wherever possible. Throughout this text runs the theme of differentials, whether culture, gender, age/developmental stage, or socio-economic, and, as acknowledged by reviewers and readers of the previous editions, our commitment to this is clearly seen in the inclusion of a whole chapter devoted to socio-economic differentials in health (Chapter 2).

## Structure of this textbook

The textbook continues to be structured into three broad sections, because they seem to work and have been well received since we started out in 2006!

The first, *Being and Staying Healthy*, contains seven chapters. In Chapter 1 we consider what is meant by 'health' or considered as 'being healthy' and examine societal and interpersonal (cognitive, and emotional) factors that contribute to this. We present a brief history to the mind–body debate which underpins much of our research. We consider the important influence of current health status, lifespan, ageing and culture on health, and in doing so illustrate better the biopsychosocial model which underpins health psychology. Chapter 2 describes how factors such as social class, income and even postcode can affect one's health, behaviour and access to healthcare. Indeed, the health of the general population is influenced by the socio-economic environment in which we live and which differs both within and across countries and cultures. Many of today's 'killer' illnesses, such as some cancers, heart disease and stroke, have a behavioural component and in Chapters 3 and 4 we describe how behaviours such as self-screening or exercise have health-protecting or enhancing effects whereas others, such as non-adherence to medicines, smoking or the use of illicit drugs, have health-damaging effects. These behaviours have been examined by health and social psychologists over several decades, drawing on several key theories such as social learning theory and socio-cognitive theory. In Chapter 5 we describe several dominant models which have been rigorously tested in an effort to identify which beliefs, expectancies, attitudes, control and normative factors contribute to health or risk behaviour. By presenting evidence of the link between behaviour and health and illness, we highlight that health psychologists have much to offer in terms of understanding or advising on individual factors to target in interventions. The section therefore ends with two chapters on intervention. Chapter 6 focuses on theories of behavioural change, setting them within the context of wider, strategic, approaches to changing behaviour. The first of these, the PRECEDE-PROCEED model is now a well-instituted public health approach to determining the targets for health behaviour change involving entire populations. The second, the 'Behaviour Change Wheel', is a more psychologically sophisticated framework for instituting change at both the individual and population level developed by Michie and colleagues. Chapter 7 goes on to consider how these theories and frameworks may be applied, and with what success in interventions designed to prevent people developing illness and poor health. It addresses interventions targeted at both individuals and whole populations.

The second section, *Becoming Ill*, contains six chapters which take the reader through the process of becoming ill: from the physiological systems that may fail in illness, that first detection of bodily change that takes us to symptom perception, interpretation and response, whether that be self-medication, lay referral behaviour or presentation to healthcare; and the psychosocial factors that may contribute to the process of becoming ill. We describe theories of coping with life stress more generally, and in examining influences on the stress experience, describe various methods of managing stress. Chapter 8 opens this section with a whole chapter dedicated to describing biological and bodily processes relevant to the physical experience of health and illness. Chapter 9 describes how we perceive, interpret and respond to bodily signs and symptoms, highlighting individual, sociocultural and contextual factors that influence the process of healthcare-seeking behaviour, including the use of lay and online referral systems (how many of us have not 'googled' our symptoms at some point?). In Chapter 10 presenting to, and communicating with, health professionals is reviewed with illustrations of 'good' and 'not so good' practice. The role of patient involvement in decision-making is an important one in current health policy and practice, and the evidence as to the benefits of patient involvement is reviewed here. The chapter also considers how health practitioners arrive at clinical decisions under time pressure and information poverty: and why they sometimes get them wrong. Chapters 11 and 12 take us into the realm of stress, something that very few of us escape experiencing from time to time! We present an overview of stress theories, where stress is defined either as an event, a response or series of responses to an event, or as a transaction between the individual experiencing and appraising the event, and its actual characteristics. We also focus on aspects of stress beyond the individual, with consideration of occupational stress, and how stress impacts on health through consideration of the growing field of psychoneuroimmunology. Chapter 12 presents the research evidence pertaining to factors shown to 'moderate' the potentially negative effect of seemingly stressful events, from distal antecedents such as socio-economic resources, social support and aspects of personality (e.g. optimism, conscientiousness), to specific coping styles and strategies. Chapter 13 turns to methods of alleviating stress, where it becomes clear that there is not one therapeutic 'hat' to fit all, as we describe a range of cognitive, behavioural and cognitive-behavioural approaches.

In the third section, *Being Ill*, four chapters are presented which draw heavily on patient and family experience derived from qualitative research as well as quantitative findings. Chapter 14 reviews the impact of illness and associated treatments on the emotions, well-being and quality of life of the individual affected, identifying the potential presence of positive as well as negative outcomes. Chapter 15 is dedicated to addressing the impact of illness and the associated treatments on the family and caregivers of these individuals – perhaps unique to health psychology textbooks. Chapter 16 addresses a phenomenon that accounts for the majority of visits to a health professional – pain – which has been shown to be much more than a physical experience. This chapter is the only disease-specific chapter in our text, but we chose to contain a chapter on pain and place it at this point towards the end of our book because, by illustrating the multidimensional nature of pain, we draw together much of what has preceded (in terms of predictors and correlates of illness, healthcare processes, etc.). Pain illustrates extremely well the biopsychosocial approach health psychologists endeavour to uphold. In a similarly holistic manner, Chapter 17 looks at ways of improving health-related quality of life by means of interventions such as stress management training, the use of social support, and illness management programmes. Finally, we close the fifth edition of this text in the same way we closed the first, with Chapter 18, which we have called From theory to practice. This chapter has changed significantly over time in that it now has three key foci: (i) how a number of psychological theories can be integrated to guide psychological interventions, (ii) how the profession of health psychology is developing in a variety of countries and the differing ways it is achieving growth, and (iii) how psychologists can foster the use of psychological interventions or psychologically informed practice in areas (both geographical and medical) where they are unused. This ends our book therefore by highlighting areas where health psychology research has or can perhaps in the future, 'make a difference'.

**Key changes from earlier editions of this book** include increased opportunity for students to engage in critical reflection and many areas of content development. To start with, major epidemiological updates and greater consideration of global health issues (such as and cultural influences on health and health behaviour are found in Chapters 1–5. In Chapter 2 we have tried to reflect more of this diversity of influences in relation to inequalities in health. In Chapters 3 and 4, as well as copiously updating the epidemiological statistics regarding health risk and health-protective behaviours (which are continually updating) and outlining current health policy and targets where they exist, we continue to describe evidence of individual, lifespan, cultural and gender differentials in health behaviours. In Chapter 4, for example, more attention is paid to global health, and to influences on immunization and screening behaviour, in part in relation to the COVID-19 pandemic. In considering theories of health and health behaviour change in Chapter 5 we give fuller consideration to the temporal dynamics of human behaviour, drawing from longitudinal data where possible to demonstrate the complexity of influences, personal, cognitive, emotional, social, on our health-related behaviours. In particular we build on predominantly socio-cognitive models to more fully address the role of emotion and how regulating our mood (or not) plays an important role in our health behaviour. Chapter 6 of the new edition has also been radically updated, with, for example, significantly more detailed coverage of the 'Behaviour Change Wheel', use of which has grown in popularity since the last edition.

In terms of covering the illness experience, Chapter 8, in addressing physiological processes, covers a broader range of illnesses, including COVID-19, updates a range of treatments, considers some individual case study examples and, in response to reviews, provides more signposts to relevant psychological content presented elsewhere in the book. In Chapter 9 we incorporate further consideration of the symptom response process, particularly how people use their 'lay referral networks'or the media when deciding whether to seek healthcare or not – the importance of this has also been highlighted during the recent COVID-19 pandemic. The general updating means that longitudinal studies of the dynamic and changing nature of illness perceptions and responses which more fully address the underlying theoretical assumptions are considered. In locating illness within a discussion of wider stress, Chapters 11 and 12 have, as elsewhere, increased coverage of cultural influences, lifespan issues and of affect regulation, and in response to reviews, occupational stress is used more often to illustrate stress processes and potential outcomes, including PTSD or burnout. We also incorporate a more positive view of stress and wellbeing, focusing on the concepts of 'positive psychology', resilience and wellbeing. Discussion of positive emotions as moderators of the stress or illness experience link us onwards to Chapter 13 where the increasingly valued concept of mindfulness and mindfulness-based interventions is introduced. In fact, positive beliefs become a recurring theme and are seen again in Chapters 14 and 15. This fifth edition further highlights research that examines the dyad's experience of health, illness and healthcare (patient–spouse most typically) demonstrating how such studies can add to our understanding and to our interventions. New to this edition is detailed consideration of caregiving motivations or willingness to care, something we need to understand better in an ageing society facing a significant 'Care Gap'. Chapters 14–17 have also seen major general updates given the wealth of research being conducted in this arena since 2016!

Given all the above, we hope you enjoy reading the book and learn from it as much as we learned while writing it. Enjoy!

## Acknowledgements

This project has been a major undertaking, conducted to a large extent while we have been home working during a global pandemic. Thank goodness for technology. The revisions have required the reading of literally hundreds of empirical and review papers published by health, social and clinical psychologists as well as ever changing statistical reports from across the globe, many books and book chapters, and many newspapers to help identify some hot health issues. The researchers behind all this work are thanked for their contribution to the field.

Many thanks also to the indomitable editorial team at Pearson Education, who have also faced many changes in recent years. Several development editors have taken their turn at the helm and guided us through tricky times where juggling academic demands and our own research has prevented us from spending time on 'the book'. Thank you to all who have pushed, pulled, and advised us up to the point where we hand over to the production team, and thanks also to the production team for meeting our image briefs and in particular that which led to our 5th cover image – readers seem to enjoy our covers and so again we stick to our theme of getting outdoors and being active. Even if some of these activities carry some risk, the goal is wellbeing and health!

Val Morrison & Paul Bennett,
October 2021

# Part I

# Being and staying healthy

# Chapter 1

# What is health?

## Learning outcomes

**By the end of this chapter, you should have an understanding of:**

- **key and current global health challenges**
- **historical models of health, illness and disability, including the mind–body debate**
- **perspectives offered by biomedical and biopsychosocial models**
- **the contribution of psychology, and specifically the discipline of health psychology, to understanding health, illness and disability**
- **the influence of lifestage, culture and health status on lay models of health and illness**
- **how health is more than simply the absence of physical disease or disability**

## Health is global

By definition, global health approaches require an understanding of health, illness and healthcare in an international context, recognising the growing diversity of national populations and the shifts in population health, depending on national policy context and healthcare investment, innovation and availability. Global health approaches recognise that significant increases in international air travel (which 'opens the world up' for individuals), brings with it a need for global health security and awareness of non-typical illnesses emerging in new contexts, e.g. symptoms of tropical disease presenting in an individual in the UK may be more slowly recognised than symptoms of a commonly seen condition.

Population diversity also calls for greater cultural sensitivity and recognition of the different explanatory models and beliefs around behaviour, health, illness and healthcare that can exist across cultures and microcultures. All of this became very evident in the context of the emergence of a novel and severe acute respiratory syndrome coronavirus (SARS-CoV-2) in winter 2019 which most readers will know is the virus leading to COVID-19 infection. Just prior to this virus emerging, the World Health Organization (WHO) had launched its new five-year strategic plan – the 13th General Programme of Work – which recognised that:

> 'The world is facing multiple health challenges. These range from outbreaks of vaccine-preventable disease like measles and diptheria, increasing reports of drug-resistant pathogens, growing rates of obesity and physical inactivity, to the health impacts of environmental pollution and climate change and multiple humanitarian crises.' (WHO, 2019).

The WHO called for society to address ten major threats to health: pollution and climate change; the rise in non-communicable diseases (e.g. diabetes, cancer, heart disease) and the role played by physical inactivity; a global influenza pandemic; antimicrobial resistance (reduced effectiveness of antibiotics); outbreaks of Ebola and high-threat pathogens; weak primary healthcare; vaccine hesitancy causing outbreaks of infectious diseases such as measles; fragile environments facing drought, famine, conflict; uncontrolled Dengue fever; continuing HIV infection. They called for these to be addressed from multiple angles and stressed that global health policies and practice should be based on sound evidence drawn from a range of disciplines: epidemiology, medicine, public health and, of course, psychological studies of human behaviour. Few readers will fail to see how this has been exemplified during the COVID-19 pandemic.

While these threats to health may vary in size and salience around the world, without doubt many will have relevance to each of us, with clear implications for human and social behaviour.

This textbook has had to quickly integrate new and emerging evidence from studies of the global COVID-19 pandemic with longer-standing evidence relating to other health threats. Across the world, common diseases, with behavioural underpinnings, are killing people in large numbers. While health and illness is primarily a personal experience, the geographical, cultural and social economic setting, the dominant government and its health policies, and even the time in which we live, all play a part in wider personal and social wellbeing.

The relevance of global health to an opener in a health psychology textbook is that the health and wellbeing challenges society faces call for evidence to inform effective intervention. We hope here to bring together evidence that can not only educate the aspiring health psychologist, but can also help inform health policy and practice – the extent to which we achieve this impact will depend on what we 'do' with our evidence as described in the final chapter.

## Chapter outline

**Around the world, in spite of huge differences in life expectancy, there is reasonable consistency in the 'top killers' in terms of disease. It is acknowledged that most, if not all, of these diseases have a behavioural component and thus potentially fall within individual influence. Knowing this does not mean behaviour will change, because humans are complex in their thoughts, emotions and actions with regards to their health behaviour.**

**This chapter introduces the common causes of mortality, before providing an historical overview of the health concept. It introduces an evolving understanding of how the mind and body interact throughout history, and the reader will learn of key models on which our discipline is founded – the biomedical and the biopsychosocial models of illness. We also illustrate how health and illness belief systems vary according to factors such as age and developmental differences, culture and cultural norms and health status. To conclude the chapter we outline the field of health psychology and highlight the questions health psychology research can address.**

# Behaviour, death and disease

The dramatic increases in life expectancy witnessed in Western countries in the twentieth century, partially due to advances in medical technology and treatments, led to a general belief, in Western cultures at least, in the efficacy of traditional medicine and its power to eradicate disease. This was most notable following the introduction of antibiotics in the 1940s (although Fleming discovered penicillin in 1928, it was some years before it and other antibiotics were generally available). Such drug treatments, alongside increased control of infectious disease through vaccination and improved sanitation, are partial explanations of increases in life expectancy seen globally.

United Nations figures show that, in 2018, worldwide the average life expectancy at birth is 72.56 years (70.39 for males, 74.87 for females), with significant and sometimes shocking variation between countries (World Bank, 2019) (see Table 1.1). Notably, within the EU this life expectancy figure is almost ten years higher, at 81 years (Eurostat, 2019). Table 1.1 presents a selection from the top and bottom of the 'league tables' with the World Bank data drawing from United Nations data and a range of national data sources. The most long-lived population continues to be located in Japan, although the figures have dropped by a couple of years over the past decade and the gender differential has widened. In Russia, the gender differential exceeds ten years. UK life expectancy at birth has increased from 47 years in 1900 to over 81 years in 2015, and is now in the top 20, which is a huge change in a relatively short period of time (WHO, 2016). Exposure to health risks and behavioural factors are thought to account for gender differences (including earlier healthcare-seeking behaviour among females) (see Chapter 9 ☛).

At the other end of this 'league table' average life expectancy drops dramatically from the low–mid 70s through to a fairly horrendous average life expectancy of just 53 years, with little gender difference, in Sierra Leone and in many other African nations.

Such life expectancy at birth statistics tell us that, in some countries, reaching a 60th birthday is simply not typical. These cultural variations can be explained to a large extent by political and environmental challenges, for example years of war or famine in some African countries, or for example in Mozambique, high HIV prevalence.

**Table 1.1** Life expectancy in selected global countries (2018)

| | Overall (years) | Male (years) | Female (years) |
|---|---|---|---|
| Japan | 84.2 | 81.1 | 87.1 |
| Spain | 83.0 | 81.0 | 86.0 |
| Australia | 83.0 | 81.0 | 85.0 |
| Greece | 82.0 | 79.0 | 84.0 |
| Sweden | 83.0 | 80.6 | 84.1 |
| Netherlands | 82.0 | 80.0 | 83.2 |
| UK | 81.0 | 80.0 | 83.2 |
| USA | 79.0 | 76.0 | 81.0 |
| Serbia | 76.0 | 74.0 | 78.0 |
| Hungary | 76.0 | 73.0 | 80.0 |
| Bulgaria | 75.0 | 72.0 | 79.0 |
| Russia | 73.0 | 68.0 | 78.0 |
| Bangladesh | 72.0 | 71.0 | 74.0 |
| Myanmar | 67.0 | 64.0 | 70.0 |
| Ethiopia | 66.0 | 64.0 | 68.0 |
| Afghanistan | 64.0 | 63.0 | 66.0 |
| Mozambique | 60.1 | 57.7 | 63.0 |
| Nigeria | 54.0 | 53.0 | 55.0 |
| Sierra Leone | 53.1 | 52.5 | 55.0 |

*Source*: World Bank, 2021.

Differences in lifestyle and diet also play a role (Chapter 3 ☛). There is some concern around rising obesity among children and the consequent health effects that may be seen in adulthood and in terms of a life expectancy a decrease in future generations. This would disproportionately affect developed countries such as the UK and the USA which have high levels of obesity and inactivity (Chapter 3 ☛). In fact, the gains in life expectancy achieved every decade within EU countries have been slowing since around 2011, with decreases seen in 19 EU countries by 2015, including UK, France, Germany and Italy. In Wales there has been a 0.1 year decline in life expectancy for both sexes since 2010 (ONS, 2017). More research is needed to explain this slowdown, as multiple factors may be at play, for example some point to the damaging effects of austerity in health spending within the UK for example (Raleigh, 2018).

It is worth noting that life expectancy is not the same as healthy life expectancy – the latter relates to whether gains in life expectancy are lived in good health as opposed to in a state of poorer health, with some illness or disability. Obviously the older you get, the lower the ratio of healthy: not healthy years a person has, for example, in Europe it is predicted that we live, from birth, about 80 per cent of our lives without disability, whereas once we are 65, only about 50 per cent of our remaining years will be lived in health (OECD, 2017). Of course, the measure of 'healthy' relies often on self-report, varies across countries and within individuals, as we discuss later in this chapter ('What does being healthy mean?').

Much of the fall in annual **mortality** rates (all causes) seen in the developed world preceded the major immunisation programmes and likely reflect public health successes following wider social and environmental changes over time. These include developments in education and agriculture, which led to changes in diet, or improvements in public hygiene and living standards (see also Chapter 2 ☛). Mortality rates within the European Union have shown an overall 25 per cent reduction since the mid-1990s, with some variations seen between Western, Eastern and central regions (and with a 'blip' increase in 2015, attributed to deaths among over-75s). Declines in some countries, for example Ireland which has seen a decline of over 30 per cent, have been attributed mainly to reductions in deaths from cardiovascular and respiratory disease, which in turn may reflect improved living standards and healthcare investment. In countries where the decline has been closer to 20 per cent, for example in Belgium, Greece and Sweden, the countries had lower rates to start with.

**mortality**

(death): generally presented as mortality statistics, i.e. the number of deaths in a given population and/or in a given year ascribed to a given condition (e.g. number of cancer deaths among women in 2020)

The physical causes of death have changed dramatically also. If people living in 1900 had been asked what they thought being healthy meant, they may have replied, 'avoiding infections, drinking clean water, living into my 50s/60s'. Death then frequently resulted from highly infectious disease such as pneumonia, influenza or tuberculosis becoming epidemic in communities unprotected by immunisation or adequate sanitary conditions. However, at least in developed countries over the last century, there has been a downturn in deaths resulting from infectious disease, and the 'league table' makes no mention of tuberculosis (TB), typhoid, tetanus or measles. In contrast, circulatory diseases such as heart disease and stroke, lung and respiratory disease are the 'biggest killers' worldwide (along with 'accidents'). These causes have been relatively stable over the past few decades. Alzheimer's disease and the dementias accounted for 12.5 per cent of deaths in England and Wales in 2019, with a higher proportion seen among females than males, explained by females living longer (Office for National Statistics, 2020).

Worldwide in 2019, the top ten leading causes of death (all ages) were recorded as listed below, with circulatory diseases, such as heart disease and stroke and other non-communicable disease (lung cancers, COPD, kidney disease, dementias, diabetes), accounting for over 44 per cent of global deaths and rising; they now make up 60 per cent of all EU deaths. Lower respiratory tract infections are the most lethal communicable disease; however these are declining, as are global deaths from neonatal conditions and diarrhoeal disease – likely due to advances in healthcare. Likewise deaths from HIV/AIDS have fallen by 51 per cent during the last 20 years, moving from the world's 8th leading cause of death in 2000 to the 19th in 2019. In contrast, diabetes has entered the global top 10 for the first time; this can largely be attributed to obesity (see Chapter 3 ☛).

Although statistics are not recorded similarly in all cases, we present comparable EU figures below (available for 2017; Eurostat, 2020). See also Figure 1.1.

Within these figures is large geographic variation (see Figure 1.1), but circulatory diseases are consistently the main causes of death. With the exception of lung cancer,

| Worldwide (WHO 2020, million) | Europe (Eurostat 2020) |
|---|---|
| Ischaemic heart disease (8.9 m) | Circulatory disease (1.7 million, heart disease and stroke; 37% of all deaths) |
| Stroke (6.2 m) | Cancers (1.2 million; 26% of all deaths) |
| COPD (3 m) | Respiratory diseases (COPD, pneumonia) 0.37 million; 8% of all deaths) |
| Lower respiratory infection (2.6 m) | Alzheimers disease and dementias (5% of all deaths) |
| Neonatal conditions (2.1 m) | |
| Trachea, Bronchus, lung cancer) (1.8 m) | Accidents (including suicide) (5% of all deaths) |
| Alzheimer's Disease and dementias (1.7 m) | Diabetes (2% of all deaths) |
| Diarrhoeal diseases (1.5 m) | |
| Diabetes mellitus (1.4 million) | |
| Kidney disease (1.3 m) | |

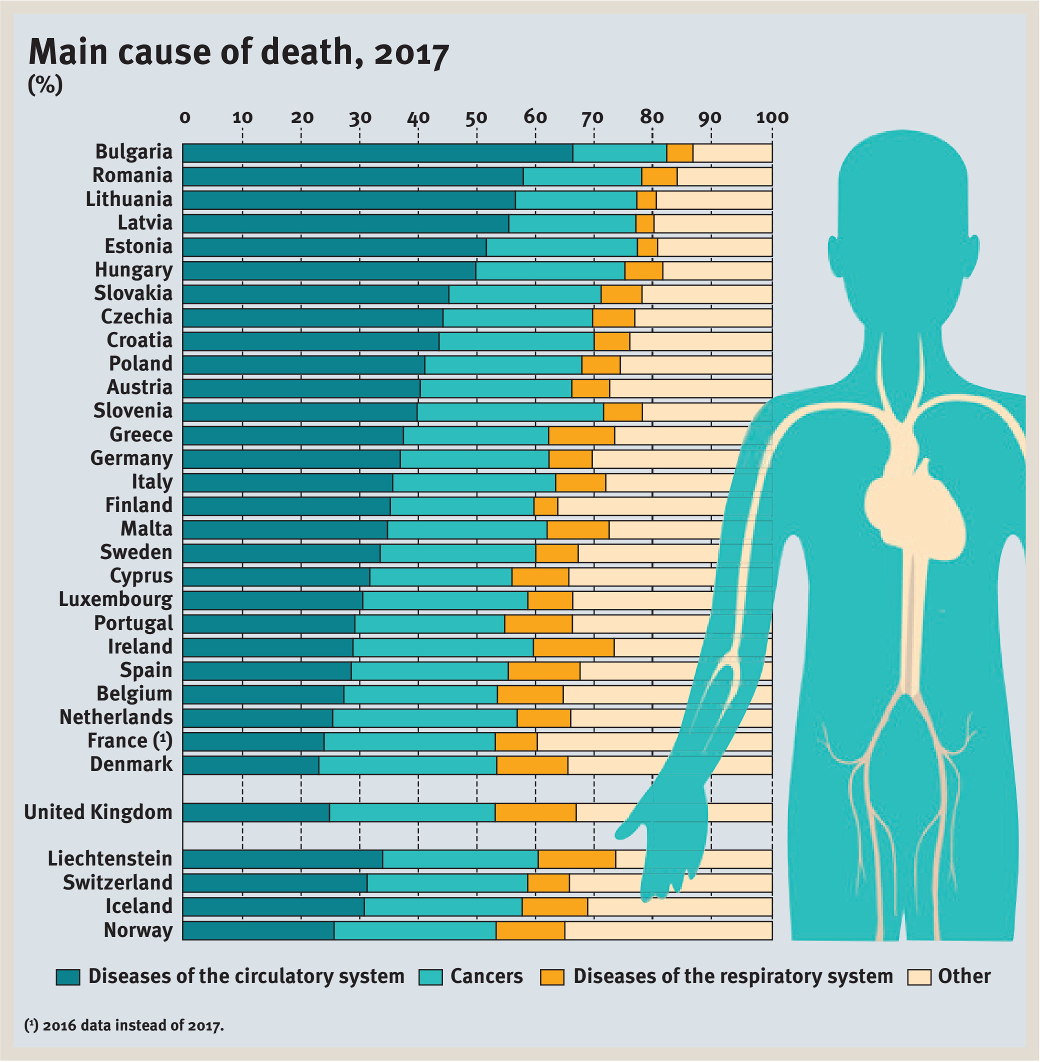

**Figure 1.1** Main causes of death in EU country, 2017

*Source*: Causes and occurrence of deaths in the EU, Eurostat.

cancer does not appear in the top ten globally; however within more developed countries, including Australia, USA and the EU, cancer is consistently placed in the top five causes of death. In some countries, for example in Denmark, Ireland, France and the Netherlands, cancers were the main causes of death (Eurostat, 2020; see Figure 1.2). EU figures attribute 26 per cent of all deaths to cancer in 2017 (23 per cent of female deaths, 29 per cent of male deaths, OECD/EU, 2020).

What has perhaps become obvious in reading this is that the leading causes of death have a behavioural component, linked, for example, to smoking, excessive alcohol consumption, sedentary lifestyles and poor diet/obesity. The higher **incidence** of cancer deaths among men are attributed to lifestyle – behaviours such as smoking and drinking plus poorer screening uptake – however, given that cardiovascular/circulatory disease deaths are in fact now higher in women, some risk behaviours in women may in fact be higher (see changes in smoking, Chapter 3 ☛). It has been known for several decades now that a significant proportion of cancer deaths are attributable, in part at least, to our behaviour, from early estimates of up to 75 per cent of those deaths (e.g. Peto and Lopez, 1990) to a more currently estimated 40 per cent (Cancer Research UK, 2021). The upturn in cancer deaths seen over the last century is also, however, due to people living longer with other illnesses they previously would have died from; thus they are reaching ages where cancer incidence is greater.

incidence

the number of new cases of disease occurring during a defined time interval – not to be confused with **prevalence**, which refers to the number of established cases of a disease in a population at any one time

There is room for optimism, however, as awareness of behavioural risks grows and behaviour changes are made (see Chapters 3 and 4 ☛) along with medical advances in treatment- UK statistics point to a significant decline (over 40 per cent for both genders) in age-standardised deaths from circulatory (heart) diseases over the past 20 years and a lower but significant (13–15 per cent ) fall for cancer and for respiratory disease, (20–26 per cent) (Office for National Statistics 2020).

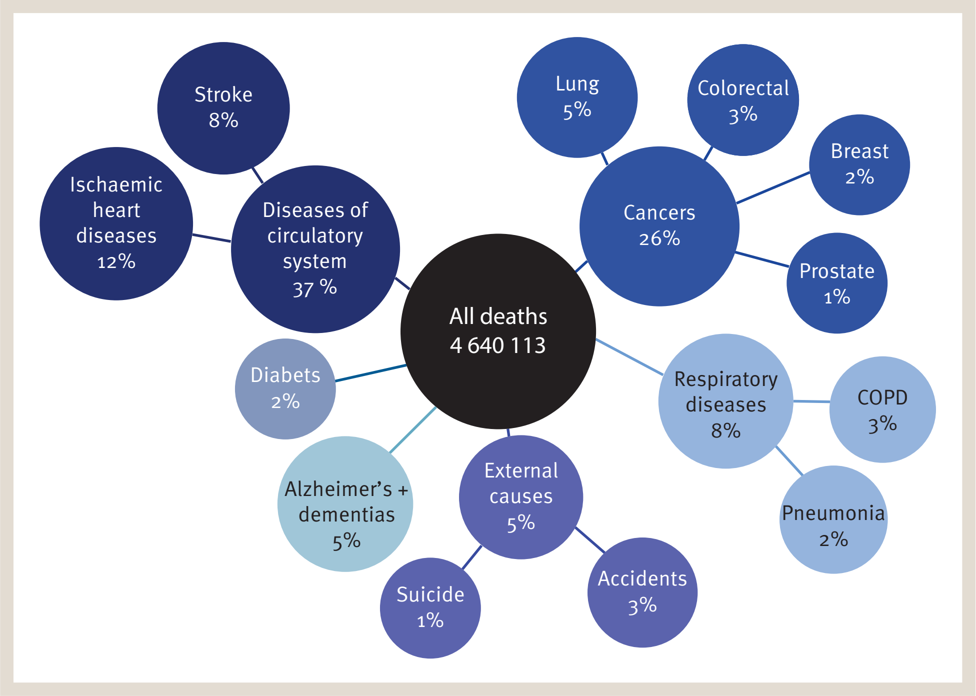

**Figure 1.2** Main causes of mortality in EU, 2017 (2016 for France)

*Source*: EU Eurostat Database 2018.

**WHAT DO YOU THINK?**

As stated above, the world is facing multiple health challenges. The COVID-19 pandemic has brought the need for investment and cooperation in responsive public health initiatives (testing, tracing, immunising), in biomedical science (vaccine and treatment development) and in our health and social care systems. To what extent do you think psychology has, and can continue to, contribute to these initiatives and our responses to them?

So, if as a reader you have been asking yourself, 'why do all these figures matter?' the answer should now be clear. Our own behaviour contributes significantly to our health and mortality. As health psychologists, gaining an understanding of why we behave as we do and how behaviour can change or be changed, is a core part of our remit. It therefore is something we discuss a lot in this and the subsequent six chapters! Key behaviours are explored more fully in Chapters 3 and 4 ☛, but the increased recognition of the role individual behaviour plays in the experience of illness is a critical starting point in this health psychology text.

First we address the evolving way of thinking about the relationship between the human mind and the human body and the dominant models of thinking about health, illness and function.

## What is health? Changing perspectives

Health is a word that most people will use without realising that it may hold different meanings for different people, at different times in history, in different cultures, in different social classes, or even within the same family, depending, for example, on age or gender. Potential differences in perspectives on health can present challenges to those concerned with measuring, protecting, enhancing or restoring health. The root word of health is 'wholeness', and indeed 'holy' and 'healthy' share the same root word in Anglo-Saxon: this is perhaps why many cultures associate one with the other: e.g. medicine men have both roles. Having linguistic roots in 'wholeness' also suggests the early existence of a view of health that included mental and physical aspects; however as we describe below, this broad view has not held dominance throughout history.

Early understanding of illness is reflected in archaeological finds of human skulls from the Stone Age where small neat holes found in some skulls have been attributed to the process of 'trephination' (or trepanation), whereby a hole was made in order to release evil spirits believed to have entered the body from outside and caused disease. Another early interpretation of disease seen in Ancient Hebrew texts is that disease was a punishment from the gods (1000–300 BC). As will be described in Chapter 9 ☛, similar beliefs remain today in some cultures. Understanding such variations in belief systems is therefore extremely important to our understanding of individuals' response to illness. Also important however is the shaping, over time, of views of the association between the mind and the body.

### Mind–body relationships

Humans have physical bodies formed of molecular, genetic, biological, biochemical and measurable components that enable the 'machine' to work, and within those they have a physical brain. However a broader concept, that of the 'mind' has been considered to be non-physical, reflecting our consciousness, thoughts and emotions that have no physical properties per se. The extent to which history has seen these existing as separate, independent entities (**dualistic** thinking) with either the body influencing the mind or the mind influencing the body, can be seen in part as the story of the development of health psychology.

The ancient Greek physician Hippocrates (*circa* 460–377 BC) considered the mind and body as linked. His humoral **theory** of illness attributed health and disease to the balance between four circulating bodily fluids (called humours): yellow bile, phlegm, blood and black bile. It was thought that when a person was healthy the

**theory**

a general belief or beliefs about some aspect of the world we live in or those in it, which may or may not be supported by evidence – for example, women are worse drivers than men four humours were in balance, and when they were ill-balanced due to external 'pathogens', illness occurred. The humours were attached to seasonal variations and to conditions of hot, cold, wet and dry, where phlegm was attached to winter (cold–wet), blood to spring (wet–hot), black bile to autumn (cold–dry), and yellow bile to summer (hot–dry). Hippocrates thought that the level of specific bodily humours related to particular personalities: excessive yellow bile was linked to a choleric or angry temperament; black bile was attached to sadness and melancholia; excessive blood was associated with an optimistic or sanguine personality; and excessive phlegm with a calm or phlegmatic temperament. Humoral theory attributed disease states to bodily functions but also acknowledged that bodily factors impacted on the mind. Healing at this time involved attempts to rebalance the humours, for example, through bleeding or starvation, or even this far back in time, through eating healthily (Helman 1978).

This view continued with Galen (*c.* AD 129–199), another influential Greek physician in Ancient Rome. Galen considered there to be a physical or pathological basis for all ill health (physical or mental) and believed not only that the four bodily humours underpinned the four dominant temperaments identified by Hippocrates but also that these temperaments could contribute to the experience of specific illnesses. For example, he proposed that melancholic women were more likely to get breast cancer, offering not a psychological explanation but a physical one because melancholia was itself thought to be underpinned by high levels of black bile. This view was therefore that the mind and body were interrelated, but *only in terms of physical and mental disturbances both having an underlying physical cause*. The mind itself was not thought to play a role in illness **aetiology**. While this view dominated thinking for many centuries, it lost predominance in the eighteenth century when organic medicine, and in particular cellular pathology, developed and failed to support the humoral underpinnings. Galen's descriptions of personality types were however still in use in the latter half of the twentieth century (Marks et al., 2000: 76–7).

During the early Middle Ages (fifth–sixth century), health became increasingly tied to faith and spirituality. At this time illness was seen as God's punishment for misdeeds or, similar to very early views, the result of evil spirits entering one's soul. Individuals were thought to have little control over their health, whereas priests, in their perceived ability to restore health by driving out demons, did. The Church was at the forefront of society at this time and so the search for non-religious, scientific explanations were slow to emerge, and in fact scientific investigation such as dissection was prohibited! The mind and body were generally viewed as working together, or at least in parallel, but due to constrained medical study, understanding developed slowly and mental and mystical explanations of illness predominated. Such causal explanations elicited treatment along the lines of self-punishment, abstinence from sin, prayer or hard work.

These religious views persisted until the early fourteenth and fifteenth centuries when a period of 'rebirth', a Renaissance, began. During the Renaissance, individual thinking became increasingly dominant and the religious perspective became only one of many. The scientific revolution of the early 1600s led to huge growth in scholarly and scientific study and consequently, the understanding of the human body, and the explanations for illness, became increasingly organic and physiological. (It should be noted that this left little room for psychological explanations however).

During the early seventeenth century, the French philosopher René Descartes (1596–1650), like the ancient Greeks, proposed that the mind and body were separate entities. Physicians acted as guardians of the body – viewed as a machine amenable to scientific investigation and explanation – whereas theologians acted as guardians of the mind – a place thought not amenable to scientific investigation! This is defined as **dualism**, where the mind exists, but is considered to be 'non-material' (i.e. conscious thoughts and feelings are not objective or visible) and independent of the body, which is 'material' (i.e. made up of real mechanical 'stuff', physical matter such as our brain, heart and cells). Where the ancient Greeks had the body 'in charge', classical dualism placed the mind in charge – the non-physical mind was thought to control the physical body and its reactions. Descartes proposed

aetiology

(etiology): the cause of disease

dualism

the idea that the mind and body are separate entities (cf. Descartes) that interaction between the two 'domains' was possible, although initially understanding of how this interaction could happen was limited, for example, how could a mental thought, with no physical properties, cause a bodily reaction (e.g. a neuron to fire) (Solmes and Turnbull 2002)? The suggested communication between mind and body was thought to be under the control of the pineal gland in the midbrain (see Chapter 8 ☛) (interactive, Cartesian dualism), but the process of this interaction was also unclear. However, because Descartes believed that the soul (the 'mind'?) left the human body at the time of death, dissection and autopsy study now became acceptable to the Church and as a result the eighteenth and nineteenth centuries witnessed a huge growth in medical understanding. Anatomical research, autopsy work and cellular pathology concluded that disease was located in human cells, not in ill-balanced humours. The dualist notion of the body as a machine (a **mechanistic** viewpoint), understandable only in terms of its constituent parts (molecular, biological, biochemical, genetic), meant that illness was understood through the study of cellular and physiological processes.

Treatment during these centuries became more technical, diagnostic and focused on physical evidence, with individuals perhaps more passively involved than previously (when at least they had been expected to pray or exorcise their demons in order to return to health). This approach underpins the **biomedical model** of illness. Within this approach, the 'mind' is considered part of the material 'stuff' by virtue of it being a function of the brain, and the study of mental processes is then mapped through physical, neural processes of the brain (this **monist materialism** reduces the mind to objectifiable brain processes, and is supported by the huge growth in neuropsychology and brain imaging research). **Behaviourism** is similarly monist, and at its extreme, rejects the study of the non-visible mind and its thought processes in favour of observeable stimuli and responses. **Humanism** (e.g. Carl Rogers) in contrast would argue that only through understanding the unique human subjective experience will we gain understanding of individual behaviour.

Where we are today in relation to mind–brain–body debates, is that we seek scientific evidence to help explain the human experience – be it objective, subjective, or demonstrating a relationship between these, although the growth in neuroscience might suggest materialism currently has the upper hand!

## Biomedical model of illness

In this model, health is defined as the absence of disease, and any symptom of illness is thought to have an underlying pathology that will hopefully, but not inevitably, be cured through medical intervention. Adhering rigidly to the **biomedical model** would lead to proponents dealing only with objective facts and assuming a direct causal relationship between illness or disability, its symptoms or underlying pathology (disease), and adjustment outcomes.

This biomedical thinking, is reflected in the World Health Organization's 1980 International Classification of Impairment, Disabilities and Handicaps (WHO IC I-D-H model, also the classification of the consequences of disease). This introduced a hierarchical model which was utilised in a large body of research exploring responses to disease. In this, impairments (abnormalities or losses at the level of a person's organs, tissues, structures or appearance), lead to disability (defined as a restriction or inability to function as 'normal for a human being') which places disability firmly within the individual, and in turn disability creates inevitable individual handicap (whereby a person experiences disadvantage in fulfilling their normal social roles).

mechanistic

a reductionist approach that reduces behaviour to the level of the organ or physical function – associated with the **biomedical model**

biomedical model

a view that diseases and symptoms have an underlying physiological explanation

monist

the idea that the non-physical mind cannot be studied separately from the physical brain

behaviourism

this approach emphasises objectifiable actions and the environmental factors that shape action/behaviour (c.f. Skinner, classical conditioning)

humanism

this approach emphasises the inner feelings and needs of individuals (c.f. Rogers, Maslow)

The assumption is that removal (i.e. treatment) of the pathology through medical intervention will lead to restored health (i.e. illness or disability results from disease either originating outside the body (e.g. germs) or through involuntary internal changes (e.g. cell mutations)). This relatively mechanistic view of how our body and its organs work, fail and can be treated, allows little room for subjectivity.

The biomedical view has been described as reductionist: i.e. the basic idea that mind, matter (body) and human behaviour can all be reduced to, and explained at, the level of cells, neural activity or biochemical activity. How then would we deal with evidence of debilitating, but medically unexplained symptoms? (see Chapter 9 ☛). What then are the implications of such a medical and positivistic/functionalistic view for the treatment of impairments (especially if we believe in a need to normalise)? For example, are cochlear implants for those with hearing impairments a more appropriate response than those around the individual with hearing difficulties learning sign language? Whose 'problem' is hearing impairment?

Reductionism also tends to ignore evidence that different people respond in different ways to the same underlying disease pathology because they vary in, for example, personality, cognition, social support resources or cultural beliefs (see later chapters).

While the biomedical model underpins many successful treatments, including immunisation programmes which have contributed to the eradication of many life-threatening infectious diseases, significant challenges to dualism, and to a purely biomedical approach exist, as we discuss more fully below.

## Challenging dualism and the emergence of (bio)psychosocial models of health and illness

In terms of mind–body associations, what is perhaps closer to the 'truth', as we understand it today, is that there is one type of 'stuff' (monist) but that it can be perceived in two different ways: objectively and subjectively. For example, many illnesses have organic underlying causes, but also elicit uniquely individual responses due to the action of the mind, i.e. subjective responses. For some people, acquiring a disability signifies the end of life, an exclusion from normal function and roles, and, as many studies have shown, increased depression. For others, disability presents a challenge, a fact of life to be lived with, rather than something which prevents them living fully (see Chapter 14 ☛). As seen in relation to developing concepts of illness, evidence of individual variation in the response to impairment and disability challenges biomedical thinking and opens the door for biopsychosocial thought. People do not inevitably become equally or similarly 'disabled' or 'handicapped' even where impairment is similar (e.g. Johnston and Pollard 2001).

While aspects of reductionism and dualistic thinking have been useful, for example, in furthering our understanding of the aetiology and course of many acute and infectious diseases, the role of the 'mind' in the manifestation of, and response to, illness is crucial to furthering our understanding of the complexities of health and illness. Psychology has played a significant role in this altering perspective. For example, a key role was played by Sigmund Freud in the 1920s and 1930s when he redefined the mind–body problem as one of 'consciousness' and postulated the existence of an 'unconscious mind' seen in a condition he named 'conversion hysteria'. Following examination of patients with physical symptomatology but no identifiable cause, and by using hypnosis and free association techniques, he identified unconscious conflicts which had been repressed. These unconscious conflicts were considered to 'cause' the physical disturbances including paralysis and loss of sensation in some patients where no underlying physical explanation was present (i.e. hysterical paralysis, e.g. Freud and Breuer 1895). Freud stimulated much work into unconscious conflict, personality and illness, linking the mind with the body and ultimately leading to the development of the field of *psychosomatic medicine* (see later section).

As a discipline, psychology has highlighted the need for medicine to consider the role played in the aetiology, course and outcomes of illness, by psychological and social factors. Consider, for example, the extensive evidence of 'phantom limb pain' experienced in amputees – how can pain exist in an absent limb? Consider the widespread acknowledgement of the placebo effect – how can an inactive (dummy) substance lead to reported reductions in pain or other symptoms which are equivalent to reductions described by those

**Photo 1.1** Having a disability does not equate with a lack of health and fitness

*Source*: flySnow/iStock/Getty Images.

receiving an active pharmaceutical substance or treatment (Chapter 16 ☛)? In addition, a linear model, such as seen in the WHO ICIDH would fail to explain how a Paralympian in spite of sensory or physical impairments, functions at a level of physical performance many of us without such impairments perform? How do we describe the person with juvenile diabetes who has ‘impairment’ in terms of pancreatic dysfunction (see Chapter 8 ☛), but as long as they adhere to medication, function as any typical adolescent, without any evidence of disability? This same juvenile may, however, skip school as a result of perceived stigma and therefore miss out on the associated social relationships and potential long-term employment benefits (i.e ‘handicap’ without disability). An individual’s context and their subjectivity in terms of beliefs, expectations and emotions interact with bodily reactions to play an important role in the illness or stress experience (see Chapter 9 ☛ in terms of symptom perception, and Chapter 11 ☛ in terms of stress reactivity).

Evidence of such changed thinking was nicely, and importantly, illustrated in an editorial in the *British Medical Journal* twenty years ago (Bracken and Thomas 2002). The authors suggested a need to ‘move beyond the mind–body split’ and noted that simply because neuroscience enables us to explore the ‘mind’ and its workings ‘objectively’ by the use of increasingly sophisticated scanning devices and measurements, this did not mean we are furthering our understanding of the subjective ‘mind’ – the thoughts, feelings and the like that make up our lives and give it meaning. Their comment that ‘conceptualising our mental life as some sort of enclosed world living inside our skull does not do justice to the reality of human experience’ (p. 1434), combined with the fact that this editorial was presented in a medical journal with a traditionally biomedical stance was evidence of a weakened Descartian ‘legacy’.

This is not to say that healthcare professionals did not believe in the role played by psychological or social factors in illness, it was just not an explicit part of their operational frameworks, nor to a large extent was it integral to their training. Shifts in thinking over time have enabled the field of health psychology to emerge, a field which adopts a biopsychosocial perspective on health, illness and disability/activity limitation which can offer potential for a range of interventions, not solely targeting pathology or physical symptomatology. This approach is reflected in this textbook.

## Biopsychosocial model of illness

The **biopsychosocial** model signals a broadening of a disease or biomedical model of health to one encompassing and emphasising the interaction between body and mind, between biological processes and psychological and social influences (Engel 1977, 1980). In doing so, it offers a complex and multivariate, but potentially a more comprehensive model with which to examine the human experience of illness. As a result of the many challenges to the biomedical approach described above, the biopsychosocial model is employed in several allied health professions, such as occupational therapy, as well as in health psychology. Although also increasingly assimilated within the medical profession there exists some pessimism that it is feasible to address all components, no matter how valuable, given constraints facing our healthcare systems (see editorial by Lane, 2014). Health is, however, recognised as more than simply the absence of disease. This text will illustrate that psychological, behavioural and social factors can add to the biological or biomedical explanations and, rather than replacing these explanations of health and illness experiences, build on them.

Reflecting these changes in thinking over recent decades, a subsequent WHO model, the International Classification of Functioning, Disability and Health (ICF, WHO 2001) takes a much broader approach than its original ICIDH model. The ICF presents a universal, dynamic and non-linear model whereby alterations in bodily structure or function (replaces impairment); activities and limitations therein (replaces disability), and participation or restrictions therein (replaces handicap) can potentially all interact and affect each other. Furthermore, the ICF recognises that the relationship between structures, activities and participation are influenced by both external, environmental and personal factors. A person's ability to perform at 'capacity' (i.e. at the best possible, given their physical status) is not solely due to the level of impairment (think of a Paralympian). Disability no longer resides within the individual, but is a response to other factors including the physical, social and cultural environment the person is trying to function within, and on their own personal characteristics, behavioural and illness related beliefs and feelings (Quinn et al. 2013) (see Chapter 9 ☛).

**biopsychosocial**

a view that diseases and symptoms can be explained by a combination of physical, social, cultural and psychological factors (cf. Engel 1977)

# Individual, cultural and lifespan perspectives on health

Given the previously presented evidence of the changes in what people are dying from, and changed views of whether and how our minds can influence our bodies, it is perhaps not surprising that views of what health is have also changed over time. In the eighteenth century, health was considered an 'egalitarian ideal', aspired to by all and potentially under an individual's control. However, doctors were available to the wealthy as 'aids' to keeping oneself well, but were less available to the poor. By the mid-twentieth century, accompanied or perhaps preceded by new laws regarding sickness benefit, and medical and technological advances in diagnostic and treatment procedures, health became increasingly and inextricably linked to 'fitness to work'. Doctors were required to declare whether individuals were 'fit to work' or whether they could adopt the 'sick role' (see also Chapter 10 ☛). Many today continue to see illness in terms of its effects on their working lives, although research increasingly addresses the opposite direction of effects, i.e. the influence work role and conditions have on illness (see discussion of occupational stress in Chapter 11 ☛).

Also perhaps changing over time is the assumption that traditional medicine can, and will, cure us of all ills. Over recent decades, many more people have acknowledged the potential negative consequences of some pharmacological treatments (consider for example long-term use of anxiolytics such as Valium), and as a result the 'complementary' and 'alternative' medicine industry has burgeoned.

Most countries are seeking, in what is known as the 'post 2015 development agenda', to better measure their populations health and wellbeing, given the changing nature of disease (from acute infectious disease to chronic disease) and the population (an ageing one). Within the United Nations, 17 Sustainable Development Goals were set as part of a 2030 Agenda for Sustainable

Development (United Nations, 2015); one of which is to ensure healthy lives and promote wellbeing at all ages. Within this goal is a specific target to reduce by one-third the premature mortality arising from non- communicable diseases through prevention and treatment and, in recognising that health is not simply about the absence of physical disease, to promote mental health and wellbeing. They seek to gain an additional two 'healthy life years' in everyone living in their member states.

## Lay theories of health

Health and wellbeing are clearly important at a policy level; however if a fuller understanding of health and illness is to be attained, it is necessary to find out what people think health and illness are. The simplest way of doing this is to ask them!

In a now classic study exploring lay perceptions of health, Bauman (1961) asked 'What does being healthy mean?'. She found that people with diagnoses of quite serious illness made three main types of response whereby being healthy was:

1. considered as a 'general sense of wellbeing';
2. identified with 'the absence of symptoms of disease';
3. seen in 'the things that a person who is physically fit is able to do'.

Bauman argued that these three types of response reveal health to be related to:

- feeling
- symptom orientation
- performance.

However it was noted that study respondents in this study did not answer in discrete categories, with nearly half of the sample providing two of the above response types, and 12 per cent using all three types. This highlights the multifaceted way in which we may think about health. In addition, Bauman's sample consisted of those with quite serious illness. We now know that current health status influences subjective views of health and reports of what 'health is'. For example, among almost 500 elderly people asked to rate factors in order of importance to their subjective health judgements, the most important factors related to physical functioning and vitality (being able to do what you need/want to do). However, the current health status of the sample (poor/fair; good; very good/excellent) influenced these judgements: those in poor/fair health based their health assessment on recent symptoms or indicators of poor health, whereas those in good health considered more positive indicators (being able to exercise, being happy). Consistent with this, subjective health judgements were more tied to **health behaviour** in 'healthier' individuals (Benyamini et al., 2003).

Although some people have been shown to find it hard to distinguish health from an absence of illness, health is generally viewed as a state of equilibrium across various aspects of the person, encompassing physical, psychological, emotional and social wellbeing (e.g. Herzlich, 1973). Bennett (2000: 67) considers these representations of health to distinguish between health as '*being*', i.e. if not ill, then healthy; '*having*', i.e. health as a positive resource or reserve; and '*doing*', i.e. health as represented by physical fitness or function (as seen in Benyamini et al.'s study above). Bauman's respondents appear to have focused more on the 'being' healthy and 'doing' aspects, which may be in part because 'having' health as a resource was not prominent in the minds of her patient sample. It does seem that health is considered differently when it is no longer present, i.e. it is considered to be good when nothing is wrong (perhaps more commonly thought in older people) and when a person is behaving in a health-protective manner (perhaps more commonly thought in younger people).

Another classic, but more representative picture of the health concept was perhaps obtained from a large, questionnaire-based Health and Lifestyles Survey of 9,003 members of the general public, of whom 5,352 also completed assessment seven years later (Cox, Huppert and Whichellow, 1993). This survey asked respondents to:

- Think of someone you know who is very healthy.
- Define who you are thinking of (friend/relative etc. – do not need specific name).
- Note how old they are.
- Consider what makes you call them healthy.
- Consider what it is like when you are healthy.

**health behaviour**
behaviour performed by an individual, regardless of their health status, as a means of protecting, promoting or maintaining health, e.g. diet

About 15 per cent could not think of *anyone* who was 'very healthy', and about 10 per cent could not describe what it was like for them to 'feel healthy'. This inability to describe what it is like to feel healthy was particularly evident in young males, who believed health to be a norm, a background condition so taken for granted that they could not put it into words. By comparison, a smaller group of mostly older women could not answer for exactly the opposite reason – they had been in poor health for so long that either they could not remember what it was like to feel well or they were expressing a pessimism about their condition to the interviewer (Radley 1994: 39).

The categories of health identified from the survey findings were:

- *Health as not ill:* i.e. no symptoms, no visits to doctor, therefore I am healthy.
- *Health as reserve:* i.e. come from strong family; recovered quickly from operation.
- *Health as behaviour*: i.e. usually applied to others rather than self; e.g. they are healthy because they look after themselves, exercise, etc.
- *Health as physical fitness and vitality*: used more often by younger respondents and often in reference to a male – male health concept more commonly tied to 'feeling fit', whereas females had a concept of 'feeling full of energy' and rooted health more in the social world in terms of being lively and having good relationships with others.
- *Health as psychosocial wellbeing*: health defined in terms of a person's mental state; e.g. being in harmony, feeling proud, or, more specifically, enjoying others.
- *Health as function*: the idea of health as the ability to perform one's duties or meet role expectations, i.e. being able to do what you want when you want without being handicapped in any way by ill health or physical limitation (relates back to the WHO concept of handicap, now described as participation/participatory restriction, described earlier, and see Figure 1.3).

Such findings suggest that health concepts are perhaps even more complex than initially thought, with evidence that the presence of health is considered as something more than physical, i.e. as something encompassing **psychosocial** wellbeing. Categories generally seem to fit with dimensions of 'being' and 'doing' and in 'health as not ill' and seem to be fairly robust (at least in Western culture; see later section for culture differences).

It also appears that subjective evaluations are typically reached through comparison with others, and in

**psychosocial**

an approach that seeks to merge a psychological (more micro- and individually oriented) approach with a social approach (macro-, more community- and interaction-oriented), for example, to health

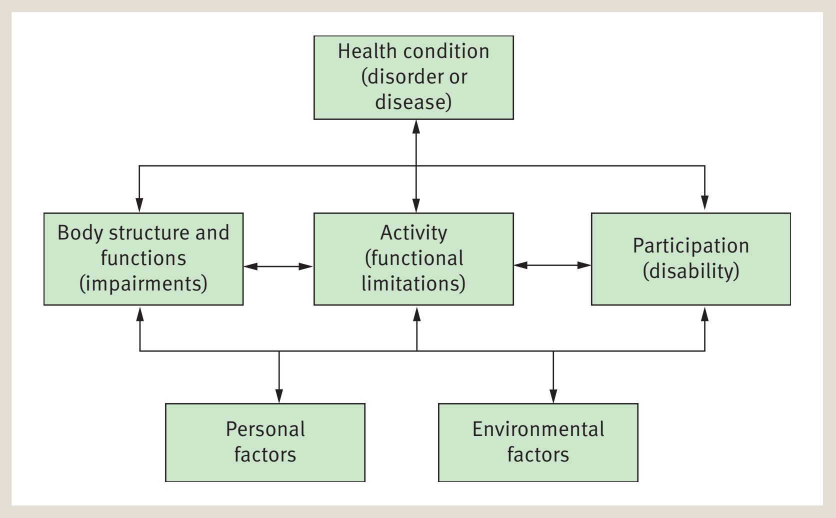

**Figure 1.3** The international classification of functioning, disability and health.

*Source*: WHO (2002b).

this way one's concept of what health is, or is not, can be shaped. For example, Kaplan and Baron-Epel (2003) found that young Israelis reporting suboptimal health did not compare themselves with people of the same age, whereas many older people in suboptimal health did compare themselves with similar aged peers. This suggests that people try to get the best out of their evaluations – a young person will tend to perceive their peers as generally healthy, so if they feel that they are not healthy, they will be less likely to draw this comparison. In contrast, older people in poorer health are more likely to compare themselves with same-aged peers, who may also have normatively poorer health, thus their own health status seems less unusual. Asking a person to consider what it is that they would consider as 'being healthy' inevitably will lead people into making these types of comparison. Health is a relative state of being.

## World Health Organization definition of health

The dimensions of health described in the preceding paragraphs are reflected in the WHO (1947) definition of health as a 'state of complete physical, mental and social wellbeing and . . . not merely the absence of disease or infirmity'. Some have questioned whether the WHO use of the term 'complete' in relation to physical wellbeing is unrealistic given the changing population age and prevalence of chronic disease and the likelihood that most of us will have some symptomatology as we age (Huber et al. 2011). That aside, the definition saw individuals as ideally deserving of a positive state, an overall feeling of wellbeing, fully functioning and has helped shape global health targets ever since and many national policy documents with their own specific targets. In general, as stated earlier in this chapter, these have, and will, set targets for reductions in deaths from the leading disease causes (i.e. heart disease, lung disease, strokes, cancer etc.) or more explicitly targeted the associated behaviours (see Chapters 3 and 4 ☛). For example in the Netherlands ('A longer and healthier life', Ministry of Health, 2003) the targets were disease incidence reductions, whereas in Belgium the targets were more behavioural: reducing smoking behaviour, fat intake, fatal accidents, increasing uptake of vaccination programmes and increasing health screening in the over-50s. Progress has been made over the past 20 years or so with reductions seen in mortality from lung, colon and prostate cancers in men, and breast and colorectal cancers in women, and reductions in drinking and smoking incidence also among young adults (see Chapter 3 ☛).

It is clear that health policy acknowledges the evidenced relationship between people's behaviour, lifestyles and their health (broadly defined). What has often been less explicitly acknowledged and addressed are the socio-economic and cultural influences on health, illness and health decisions which is why we have, ever since this textbook first emerged in 2006, dedicated a full chapter to these important influences to build this awareness (see Chapter 2 ☛). More recently the focus has in fact shifted to policies that recognise the social determinants of health and illness as well as the individual determinants, for example in the UK the Health Foundation introduced a 'healthy lives strategy' in 2017 (Health Foundation, 2017) that prioritises health as an asset rather than ill health as a burden and in doing do seeks to promote social policies that promote health lifestyles. This fits with the Public Health England campaign for Better Health 2020 and 2021 (Public Health England, 2021) (see Chapters 3 and 4 ☛).

Other more context-aware definitions of health do exist, for example Bircher (2005) defines health as 'a dynamic state of well-being characterized by a physical and mental potential, which satisfies the demands of life commensurate with age, culture, and personal responsibility'. This view places the individual centrally in the experience of health and illness whereas the WHO definition does not. Individual beliefs play a major role in the experience of health, illness, and disability. Furthermore health should not be seen in one dimension or in black or white, but instead as something experienced on a continuum from optimal wellness, through minor and major illness, to death, as described by Antonovsky (1987). The fascination for many health psychologists is how people respond differently to experiences along this continuum and how health psychology can help identify factors that might help to optimise health or reduce the negative impact of illness.

## Cross-cultural perspectives on health

What is considered to be 'normal' health varies across cultures and as a result of the economic, political and cultural climate of the era in which a person lives. Cultures vary in their health belief systems, health attributions and health practices. Think of how pregnancy is treated in most Western civilisations (i.e. medicalised) as opposed to many developing regions (naturalised). The stigma of physical disability, mental illness, or of dementia, among African, South Asian communities, and some Eastern European groups, may have consequences for the family which would not be considered in Caucasian families: for example, having a sibling or a child with a disability, or a relative with dementia or depression, may affect siblings' marriage chances or the social standing of the family (Ahmad, 2000; Grischow et al., 2018; Mackenzie, 2006). Such beliefs, often related to negative attributions of illness causality and blame, can influence disclosure of symptoms and health-seeking behaviour (Vaughn et al., 2009) (see Chapter 9 ☛).

Westernised views of health differ in various ways from conceptualisations of health in non-Westernised civilisations. In an early work, Chalmers (1996) astutely noted that Westerners divide the mind, body and soul in terms of allocation of care between psychologists and psychiatrists, medical professions and the clergy, whereas in some African cultures, these three 'elements of human nature' are integrated in terms of how a person views them, and in how they are cared for. This holistic view is similar to that found in Eastern and in Aboriginal Australian cultures (e.g. Swami et al. 2009) where the social (e.g. social and community norms and rituals) as well as the biological, the spiritual and the interpersonal, are integral to explaining health and illness states.

Spiritual wellbeing as an aspect of health has gained credence following inclusion in many quality of life assessments (see Chapter 14 ☛), and, although faith or God's reward may sometimes be perceived as supporting health, attributing one's health to a satisfied ancestor may nonetheless raise a few eyebrows if stated aloud. Negative supernatural forces such as 'hexes' or the 'evil eye' sometimes share the blame for illness and disability. For example, Grischow and colleagues' review of stigma and disability in Ghana (Grischow et al., 2018) reveals evidence that a child's disability may be perceived as a punishment for parental wrongs, and among Hindus and Sikhs, in particular, it has been reported that disability and even dementia may also be considered a punishment for past sins within the family (Katbamna et al., 2004; Mackenzie, 2006). Such belief systems can have profound effects on living with illness or, indeed, caring for someone with an illness or disability – in Ghana, children with disability may be viewed as non-human 'spirit-children', although thankfully related infanticide is thought to be low (Grischow et al., 2018).

In addition to beliefs of spiritual influences on health, studies of some African regions consider that the community or family work together for the wellbeing of all. This **collectivist** approach to staying healthy and avoiding illness differs from our **individualistic** approach to health (consider how long the passive smoking evidence was ignored, or more recently, arguments played out on social media and in policy around imposing mask-wearing to protect others from potential **coronavirus** transmission). Generally speaking, Western European cultures are found to be more individualistic, with Eastern and African cultures exhibiting more **holistic** and collectivist approaches to health. For example, in a study of

**collectivist**

a cultural philosophy that emphasises the individual as part of a wider unit and places emphasis on duties above rights, with actions motivated by interconnectedness, reciprocity and group membership, rather than individual needs and wants

**individualistic**

a cultural philosophy that places responsibility at the feet of the individual and emphasises rights above duties; thus behaviour is often driven by individual needs and wants rather than by community needs or wants

**coronavirus**

one of a group of RNA viruses that cause a variety of diseases – most recently SARS-CoV-2 virus has caused COVID-19 disease (SARS: severe acute respiratory syndrome)

**holistic**

root word 'wholeness'; holistic approaches are concerned with the whole being and its wellbeing, rather than addressing the purely physical or observable.

preventive behaviour to avoid endemic tropical disease in Malawians, the social actions to prevent infection (e.g. clearing reed beds) were adhered to more consistently than the personal preventive actions (e.g. bathing in piped water or taking one's dose of chloroquine) (Morrison et al. 1999). Collectivist cultures emphasise group needs and find meaning through links with others and one's community to a greater degree than individualistic ones which emphasise the uniqueness and autonomy of its members i.e. promote and validate 'independent selfs' (Morrison et al. 1999: 367). This belief in a community of individuals working together for the good of all can however lead to problems if a person is ill or disabled and considered unable to contribute, with consequent stigma, disenfranchisement and sometimes even the experience of personal harm (Grischow et al. 2018).

Cultures that promote an interdependent self are more likely to view health in terms of social functioning rather than simply personal functioning, fitness, etc. For example classic studies by George Bishop and colleagues (e.g. Bishop and Teng, 1992; Quah and Bishop 1996) noted that Chinese Singaporean adults view health as a harmonious state where the internal and external systems are in balance, and, on occasions where they become imbalanced, health is compromised. Yin – the positive energy – needs to be kept in balance with the yang – the negative energy (also considered to be female!). Other Asian cultures, e.g. the Vietnamese, use mystical beliefs relating to maintaining balance between poles of 'hot' and 'cold'. In Eastern cultures illness or misfortune is commonly attributed to predestination; African Americans and Latinos are more likely than White Americans to attribute illness causes externally (e.g. to the will of God) (e.g. Vaughn et al., 2009).

**Photo 1.2** Visiting a herbalist to choose individually tailored remedies.

*Source*: Marcus Chung/E+/Getty Images.

Clearly, therefore, to maximise effectiveness of health promotion efforts, it is important to acknowledge the existence and effects of such different underlying belief systems and resultant behaviours (see Chapters 6 and 7 ☛). It is also worth noting that variations exist within as well as between, cultures, especially where there may have been exposure to multiple cultural influences for example as reported by Wong et al. (2011) from studies in Singapore where both Asian and Western influences coexist but have differential effects on subjective wellbeing ratings. In the Western world, the perceived value of alternative remedies for health maintenance or treatment of symptoms is seen in the growth of alternative medicine and complementary therapy industries; however, Western medicine dominates. In contrast, in non-Western countries a mixture of Western and non-medical/traditional medicine can often be found. For example in Malaysia, while Western-style medicine is dominant, traditional medicine practice by 'bomohs' (faith healers) is available (Swami et al., 2009). Similarly among some Aboriginal tribes spiritual beliefs in illness causation coexist with the use of Western medicines for symptom control (Devanesen, 2000), with traditional medicine and healing processes consistent with cultural and spiritual beliefs still used by some in the treatment of cancer (Shahid et al., 2010).

These examples illustrate that the biomedical view is acknowledged and assimilated within different cultures' belief systems, and show that, while access to and understanding of Western medicines' methods and efficacy grows, better understanding of culturally relevant cognitions regarding illness and health behaviour is needed (see Kitayama and Cohen, 2007; Vaughn et al., 2009). We also need more research which considers the role religion plays in health across and within cultures. Swami et al. (2009) for example, in their study of 721 Malaysian adults, found that Muslim participants had higher beliefs in religious factors and fate as influences on recovering from illness than did Buddhist or Catholic participants and they were also more likely to believe that their likelihood of becoming ill was uncontrollable. As we will discuss in a later chapter (Chapter 9 ☛), responses to symptoms, including the use of healthcare either traditional or Western, will in part be determined by the nature and strength of such cultural values and religious beliefs. Illness discourse will reflect the dominant conceptualisations of individual cultures and religions, and, in turn, how people think about health and illness will shape expectations, behaviour, and use of health promotion and healthcare resources. Chapter 2 ☛ will describe the social inequalities in health and address further cultural and social economic influence, but one issue worth noting here is that of **social exclusion**, defined by Macleod et al. (2016). Poor health has been confirmed as both a predictor and as an outcome of social exclusion based on data from four waves of data from Understanding Society, the UK Household Longitudinal Study (Sacker et al, 2017). Those from minority cultures, and also those of older age, are more likely to be socially excluded.

## Lifespan, ageing and beliefs about health and illness

Psychological wellbeing, social and emotional health are affected by illness, disability, treatments and hospitalisation, which can be experienced at any age. While growing older may be associated with decreased functioning and increased disability or dependence, it is not of course only older people who live with chronic illness: think of childhood asthma, juvenile arthritis, or diabetes, for example. If health professionals are to promote the physical, psychological, social and emotional wellbeing of their patient or client whatever their age, then some understanding of 'typical' cognitive and psychosocial development will be helpful in cases where illness may have disrupted this. The subsequent section introduces lifespan issues in relation to health perceptions, but it is recommended that interested readers also consult a developmental health psychology text for fuller coverage (e.g. Turner-Cobb, 2014).

### Developmental theories

The developmental process is a function of the interaction between three factors:

1. *Learning:* a relatively permanent change in knowledge, skill or ability as a result of experience.
2. *Experience:* what we do, see, hear, feel, think.
3. *Maturation:* thought, behaviour or physical growth, attributed to a genetically determined sequence of development and ageing rather than to experience.

**social exclusion**

a multidimensional process through which individuals become disengaged from mainstream society, depriving people of the rights, resources and services available to the majority

### STOP and THINK

Conclusions reported in textbooks such as this are only based on what is reported in the research (i.e. in survey responses). As noted by a large European statistics reporting body (*Health at a Glance*, OECD/EU, 2018, p. 98): 'Cross-country differences in perceived health status can be difficult to interpret because social and cultural factors may affect responses.' The way in which certain behaviours are viewed can vary across cultures, and also shift over time and this may affect self-reporting. For example, mainstream views of alcohol dependence have shifted from it being viewed as a legal and moral problem, with abusers seen as deviant, to a disease, with alcohol dependent patients treated in clinics. Similarly smoking, once viewed as a glamorous, even desirable behaviour (1930s–1980s), is now more commonly viewed as socially undesirable and indicative of a weak will – perhaps reflecting this, the smoking prevalence has declined. Furthermore, what is normal (or deviant) and what is defined as sick (reflecting illness) in a given culture can have consequences for how others respond: consider how societal responses to illicit drug use have ranged from prohibition through criminalisation to an illness requiring treatment (see Chapter 3 ☛).

An early maturational framework for understanding cognitive development (Piaget, 1930, 1970) provides a good basis for understanding the developmental course of concepts regarding health, illness and health procedures. Piaget proposed a staged structure to which, he considered, all individuals follow in sequence as below:

1. *Sensorimotor* (birth–2 years): an infant understands the world through sensations and movement, and moves from reflexive to voluntary action, but lacks symbolic thought.
2. *Preoperational* (2–7 years): symbolic thought develops, enabling imagination and intellectual development through the emergence of simple logical thinking, play and language, although preoperational children are generally **egocentric**.
3. *Concrete operational* (7–11 years): logical thought develops; can perform mental operations (e.g. mental arithmetic) and manipulate objects to enable problem-solving; others' perspectives can also be understood.
4. *Formal operational* (age 12 to adulthood): abstract thought and imagination develop as does deductive reasoning, metacognition and introspection. Not everyone may attain this level.

Piaget's work was influential in terms of providing an overarching structure within which to view cognitive development although it has been noted that he may have underestimated children's capacities and also the role complex adult language and communication play in a child's development. In this regard and of more relevance here, is work that more specifically addresses children's developing beliefs, understanding and expression of health and illness constructs.

Erik Erikson (Erikson 1959; Erikson et al. 1986) described eight major life stages (five related to childhood development – infancy, early childhood, preschool, school age, adolescence, and three related to adult development – young adulthood, middle adulthood, maturity). Each stage varies across different dimensions, including:

- cognitive and intellectual functioning;
- language and communication skills;
- the understanding of illness;
- healthcare and maintenance behaviour.

Each of these dimensions is important to the health psychologist and to healthcare practitioners. Deficits or limitations in cognitive functioning (due to age, accident or illness) may, for example, influence the extent to which an individual can understand or execute medical instructions, report their symptoms or emotions or even have their healthcare needs assessed. Children's acquisition of language is fundamental to their development as it enables interaction in their social world and thus social development (Vygotsky, as reported in Daniels, 1996). Communication deficits or limited language skills can impair a person's willingness to place themselves in social situations, or impede their ability to express their pain or distress to health professionals or family members. Intellectual development further affects the understanding an individual has of their symptoms or their illness which is also crucial to their healthcare-seeking behaviour and to their adherence with any healthcare intervention. Finally, behaviour, specifically health-risk or health-enhancing behaviour, also varies across the lifespan and influences one's perceived and/or actual risk of illness. Cognitive, communicative and behavioural aspects with relevance to health and illness experience are extensively covered in this textbook but we cannot assume that explanations or models of adult thoughts, feelings or behaviour can be applied to children, given normative cognitive development, or to adolescents, given variations in the salience of social influence (Holmbeck, 2002). We present some further details of child development as relevant to health and illness concepts here using Piagetian stages as a broad framework.

egocentric

self-centred, such as in the preoperational stage (age 2–7 years) of children, when they see things only from their own perspective (cf. Piaget)

## Sensorimotor and preoperational stage children

Little work with infants at the sensorimotor stage is possible in terms of identifying health and illness cognitions, as language is very limited. At the preoperational stage, children develop linguistically and cognitively, and symbolic thought means that they develop awareness of how they can affect the external world through imitation and learning, although they remain very egocentric. In preoperational children, health and illness are considered in black and white, i.e. as two opposing states rather than as existing on a continuum. Children are slow to see or adopt other people's viewpoints or perspectives i.e. they lack a 'theory of mind', which is crucial if one is to empathise with others. Thus a preoperational child is not very sympathetic to an ill family member, not understanding why this might mean they receive less attention.

### Illness concept

It is important that children learn over time some responsibility for maintaining their own health; however, few studies have examined children's conception of health which would be likely to influence their health behaviour. Research has however examined the developing illness concept. Bibace and Walsh's (1980) findings from children aged 3–13 years suggested that an illness concept develops gradually. Children were asked questions about illness *knowledge* – 'What is a cold?'*; experience* – 'Were you ever sick?'; *attributions* – 'How does someone get a cold?'; and *recovery* – 'How does someone get better?' Responses revealed a progression of understanding and attribution for causes of illness, and six developmentally ordered descriptions of how illness is defined, caused and treated emerged.

Under-7s generally explained illness on a 'magical' level – explanations are based on association:

- *Phenomenonism:* until around 4 years old, illness was a sign or sound that the child has at some time associated with illness, but with little grasp of cause and effect: e.g. a cold is when you sniff a lot.
- *Contagion*: from around age 4, illness was caused by a person or object that is close by, but not necessarily touching the child; or it can be attributed to an activity that occurred before the illness: e.g.: 'You get measles from people'. If asked *how*? 'Just by walking near them'.

## Concrete operational stage children

Piaget described children over 7 as capable of thinking logically about objects and events, although they are still unable to distinguish between mind and body until around age 11.

### Illness concept

Bibace and Walsh found explanations of illness among 8 to 11 year olds to be more concrete and based on a causal sequence:

- *Contamination:* i.e. children understand that illness can have multiple symptoms, and they recognise that germs, or even their own behaviour, can cause illness: e.g. 'You get a cold if you get sneezed on, and it gets into your body'.
- *Internalisation:* i.e. illness is within the body, and the process by which symptoms occur is partially understood. The cause of a cold may come from outside germs that are inhaled or swallowed and enter the bloodstream. These children *can* differentiate between body organs and function and can understand specific, simple information about their illness.

In this concrete operational stage, medical staff are still seen as having absolute authority, but children can also see the role of personal action as returning them to health. Children can now begin to weigh up the pros and cons of actions and medical staff actions might be criticised/avoided: e.g. reluctance to give blood, accusations of hurting unnecessarily. Importantly children here can be encouraged to take some personal control over their illness or treatment – which can help the child to cope. They also need to be encouraged to express their fears and to recognise the importance of communication. Parents need to strike a balance between monitoring a sick child's health and behaviour and being overprotective, as this can detrimentally affect a child's social, cognitive and personal development and may encourage feelings of dependency and disability (see Chapter 15 ☛ for further discussion of coping with illness in a family).

## Adolescence and formal operational thought

Adolescence is a socially and culturally created concept only a few generations old, and indeed many primitive societies do not acknowledge adolescence, and instead children move from childhood to adulthood with a ritual performance rather than the years of transition Western societies consider a distinct period in life. Puberty is a period of both physical and psychosocial change. During early adolescence (11–13 years), as individuals prepare for increased autonomy, independence and peers take on more credence than parents, much of life's health-damaging behaviour commences, e.g. smoking (see Chapter 3 ☛).

### Illness concept

Bibace and Walsh describe illness concepts at this stage as being at an abstract level, based on interactions between the person and their environment:

- *Physiological:* children now reach a stage of physiological understanding where most can define illness in terms of specific bodily organs or functions (e.g. germs cause white blood cells to get active to try and fight them), and begin to appreciate multiple physical causes, e.g. genes plus pollution plus behaviour.
- *Psychophysiological:* in later adolescence (from around 14 years) and in adulthood, many people grasp the idea that mind and body interact, and understand or accept the role of stress, worry, etc. in the exacerbation and even the cause of illness. However, many people of all ages fail to achieve this level of understanding about illness and continue to use more cognitively simplistic explanations.

It should be noted that Bibace and Walsh's study focuses predominantly on the issue of illness causality. Extending illness cognitions further, other work has shown that children and young people are able to think about health and illness in terms of other dimensions, such as controllability and severity (e.g. Forrest et al., 2006; Gray and Rutter, 2007) (see Chapter 9 for fuller discussion of illness perceptions ☛).

Adolescents perceive more personal control over the onset and course of illness and are more aware that their actions can influence outcomes. Advice and interventions are more fully understood as are complex remedial and therapeutic procedures: e.g. they understand that taking blood can help monitor the progress of a disease or a treatment. They may, however, choose to be non-adherent if treatment is thought to disrupt one's goals or lose peer approval, or if they are mistrustful of the confidentiality around their heath disclosures to a health professional (Berlan and Bravenderm, 2009). In addition any efforts to minimise a child's autonomy (from pre-adolescence onwards) can be counterproductive (Holmbeck et al., 2002).

Overall, childhood sees the development of health and illness concepts and of attitudes and patterns of health behaviour which impact on the person's future health status (see Chapter 3 ☛). How children communicate their symptom experience to parents and healthcare staff, their ability to act on health advice, and the level of personal responsibility for disease management taken is, according to such staged theories, determined by the level of cognitive development attained. This approach has not met with universal support whereby illness concepts are thought to derive from a range of influences, such as past experience and knowledge, rather than from relatively fixed stages of cognitive development. Illustrating this point, a survey of 1,674 Canadian children aged 5–12 years old (Normandeau et al., 1998) which asked participants to consider health in terms of their daily experiences (what signified good health in their friends; what behaviours are necessary to be healthy; what the consequences are of being healthy, and what things are dangerous to health) identified they held three main criteria for good health:

1. being functional (practising sports, absence of disease);
2. mental health (wellbeing, looking healthy, feeling good about oneself, good relationships with others);
3. lifestyle health behaviour (healthy diet, good hygiene, sleeping well).

The child's age was found to effect some components of these dimensions: for example, among older children functionality was more associated with sports participation and physiological functioning, whereas in younger children it was more related to 'going outside'. Older children also considered 'not being sick' as more important. In terms of lifestyle behaviour, older children more often referred to good diet than did younger children; and in terms of mental health, older children more often referred to self-concept, whereas younger children referred more to the quality of relationships with others. No effects were found in terms of gender or socio-economic background. In the context of this section on life stage and health concept, the important finding is that children as young as 5 elicited multidimensional concepts of health that were more complex than suggested by a shift from concrete to abstract thinking as described by stage theorists. Very early on, children's conceptions

**Photo 1.3** Which of these are healthy? You can't always tell by looking. Neither would you know by looking which of these rated themselves as 'extremely healthy' would you? Health is more than objective symptoms.

*Source*: Syda Productions/Shutterstock.

### WHAT DO YOU THINK?

Is middle age simply a state of mind? Are you 'as young as you feel'? Think of your parents, aunts and uncles or of family friends in their 40s. Do they seem to share outlooks on life, expectancies and behaviours that are significantly different to those of you and your friends? How do you view growing older? Think about how it makes you feel and question these feelings.

included a mental health dimension, which is contrary to that found in early research. Perhaps the methodology of inviting children to talk about their concepts in relation to their own lives and experience as opposed to more hypothetical questioning, accounts for this difference. In addition, the way in which children are spoken to or in which questions are asked may impact on their understanding and thus their responses. Communicating with children about their health, illness, or any necessary treatments needs to be age appropriate (e.g. Leonhardt et al., 2014).

## Adulthood 17/18

Adulthood tends to be divided between early (17–40), middle age (40–60) and elderly (60/65). Early adulthood blends out of adolescence as the person forges their identity and assumes the roles and responsibility of adulthood – a time of consolidation. In contrast to the years from 3–13 which Laslett (1991) describes as the '1st age', where dependency, childhood and education are key, adolescence and adulthood is considered as the '2nd age', a period of developing independence, maturity and responsibility. Early adulthood typically sees all sorts of transitions, such as graduating from school and college, taking on new careers, pregnancy, marriage, childbirth; many will divorce, some will lose a parent. Although Piaget did not describe further cognitive developments during adulthood, new perspectives develop from experience across the lifespan, and what is learned is ideally applied to achieving future life goals. In relation to health, adults are less likely than adolescents to adopt new health-risk behaviour and are generally more likely to engage in protective behaviour: e.g. screening, exercise, etc. for health reasons (see Chapter 4 ☛).

In contrast to generally positive views of early adulthood, middle age has been identified as a period of doubt and anxiety, reappraisal and change. Some of this may be triggered by uncertainty of one's role when children become adults and leave home, i.e. 'the empty nest' syndrome, and some by awareness of physical changes associated with ageing – greying hair, weight gain, stiff joints, etc. On a positive note these perceptions of ageing can trigger positive health behaviour change (see Chapter 3 and 4 ☛).

## Ageing and health

In the UK, as elsewhere in the world, the ageing population (accepting the cut-off age for 'older people' to be 60 or over) has burgeoned, but more particularly the percentage of persons living into their late 70s or 80s has increased and is projected to increase further. Worldwide 11.7 per cent of the population are aged over 60 years (compared to 8.6 per cent in 1980); 7 per cent over 65 years, and 1.7 per cent are over 80 years old – this latter percentage translates to 120,199,000 individuals (>120 million) (United Nations, 2013). A worldwide increase is expected in the proportion of the population aged over 65. Within the UK (ONS, 2018), projections are that by 2030 about a fifth of the population will be aged 65 or older, and a further 10 per cent will be over the age of 75. Globally the United Nations predict a 7.6 per cent increase in those aged 60+ by 2050, with older people outnumbering children by 2047 and representing half of those defined as 'dependants' by 2075.

The shift in proportions of older persons living in our society is underpinned by many factors, including reduced birth numbers/slower population growth, as well as the reasons associated with longer life expectancy cited earlier. The implications for health and social care resources are obvious, given the **epidemiology** of illness: i.e. the fact that the incidence of many diseases increases with longevity. Of course, not all become ill or infirm as they enter older age; in fact Laslett (1996) describes the '3rd age' of those aged 65+ as a period of fulfilment. However, the English Longitudinal Study of Ageing (see also Chapter 14 ☛) (Steptoe et al., 2012), notes that an increased risk of dying prematurely is associated with poorer enjoyment of life. This highlights the role of subjective wellbeing, whatever the age. The '4th age', however, is more strongly associated with disability and dependence, relating to the 'oldest old' of those aged over 80 where health does decline more rapidly.

In an ageing society disability is common; 85 per cent may experience some chronic condition (Woods, 2008), with the main problems being associated with memory loss, incontinence, depression, falls or immobility (UN, 2014). Does the process of ageing influence how an older person thinks about themselves and their health?

Empirical research has shown that **self-concept** is relatively stable through ageing (e.g. Baltes and Baltes, 1990; Coleman, 1999) and that changes in self-concept are not an inevitable part of the ageing process. While growing older may present an individual with new challenges, this should not be seen as implying that ageing is itself a problem, in spite of the ageist attitudes that exist in many industrialised countries.

**epidemiology**

the study of patterns of disease in various populations and the association with other factors such as lifestyle factors; key concepts include mortality, morbidity, prevalence, incidence, absolute risk and relative risk. Type of question: Who gets this disease? How common is it?

**self-concept**

that knowledge, conscious thoughts and beliefs about yourself that allow you to feel you are distinct from others and that you exist as a separate person

The elderly often report expecting to have poor health. Such expectations can result in poor healthcare checks and maintenance as they regard health protective behaviour as pointless. They may think loss of mobility, poor foot health and poor digestion are an inevitable and unavoidable part of ageing and so may not respond to symptoms as they should (e.g. Sarkisian et al., 2001). Exercise tends to decline in old age in the belief that it will overexert the joints, heart, etc. In fact, the elderly tend to underestimate their own physical capacities, yet as we shall see in Chapter 4 ☛, exercise is both possible and beneficial. Even in the face of 'objective' signs of illness, many older people retain a positive view of their health. If we can identify factors associated with 'successful ageing', then health promotion efforts can target the factors associated with this. What is 'successful ageing'?

## Successful ageing

Bowling and Iliffe (2006) describe five progressively more inclusive 'models' of successful ageing and the variables considered within each model. Variables were all categorised or dichotimised: e.g. presence/absence of diagnosis; sense of purpose/no sense of purpose, etc., in order for each model to identify whether a person was 'successfully aged' or not:

*Biomedical model*: based on physical and psychiatric functioning – diagnoses and functional ability.

*Broader biomedical model*: as above but includes social engagement and activity.

*Social functioning model*: based on the nature and frequency of social functioning and networks, social support accessed.

*Psychological resources model*: based on personal characteristics of optimism and self-efficacy and on sense of purpose, coping and problem solving, self-confidence and self-worth (see Chapter 12 ☛ for a discussion of many of these positive cognitions).

*Lay model*: based on the above variables plus socio-economic variables of income and 'perceived social capital', which included access to resources and facilities, environmental quality and problems (e.g. crime, traffic, pollution, places to walk, feelings of safety).

The study assessed all the above variables in a sample of 999 individuals aged over 65 years and assigned them either as successfully aged or not based on achieving the ‘good’ score on each variable, e.g. no physical conditions versus one or more. The authors then tested which of these models ‘best’ distinguished those participants that rated quality of life (QoL) as ‘Good’ (included ‘So good, could not be better’, or ‘Good’) instead of ‘Not good’ (included ‘Alright’ or ‘So bad, could not be worse’). Although each model could independently predict QoL (Chapter 15 ☛), the strongest prediction was achieved by the lay model. Those individuals who scored as ‘successfully aged’ on the basis of lay model variables were more than *five* times more likely to rate their QoL as ‘Good’ rather than ‘Not good’. The odds of a ‘good’ QoL rating versus ‘not good’ was next best among those classified on the broader biomedical model (3.2 × more likely), than the biomedical model (2.6 × more likely), the psychological (2.4 × more likely) and social models (1.99 × more likely).

Such findings highlight the importance of multidimensional models of health in that medical or psychological or social variables are all important, but a more holistic model is ‘better’. A broader model also opens up a range of opportunities for intervention; the challenge now is to use such findings to develop and evaluate health promotion interventions with older populations (see Chapters 6 and 7 ☛). Of note, however, is that the sample in this study was 98 per cent white and thus the model of successful ageing best associated with QoL in this sample may not hold for non-white samples.

## IN THE SPOTLIGHT

### Measuring self-rated or subjective health status

Health is commonly viewed in terms of how we feel and what we do. Our ‘health status’ is not simply whether we are alive or dead, nor is it defined simply on the basis of the presence or absence of symptoms – it is something we perceive for ourselves, sometimes referred to as ‘subjective health status’. In fact, generally the relationship between subjective health and markers of ‘objective’ health is weak (e.g. Berg et al., 2006); however, self-ratings of health (SRH), often assessed as a simple single item (e.g. ‘How is your health in general? Is it very good, good, fair, bad, very bad?’), have been found to predict major health outcomes, including mortality (e.g. Bond et al., 2006; Sargent-Cox et al., 2010). In almost all European countries a majority of the adult population will rate their health as good or very good, although this does not mean that the actual health within the countries depicted is ‘objectively’ better (OECD, 2018). These are self-reports, and with this type of data come some challenges.

For example, data are potentially influenced by the age composition of the sample, as older people generally report poorer health and furthermore the same associations are not always found for both genders. Across all EU countries sampled for the data presented above (OECD, 2018), men were more likely to rate their health as good or better, and rating declined markedly after age 45 in many countries and then again after age 65 (see also Figure 1.4). Socio-economic influences on health experiences and SRH reports are also reported (OECD, 2018; Link et al., 2017) (see Chapter 2 ☛) whereby nearly 80 per cent of those in the highest income quintile report good health, compared to about 60 per cent of those in the lowest income quintile.

Addressing measurement issues, Sargent-Cox and colleagues conducted a study of over 2,000 Australian adults over the age of 65 assessed seven times between 1992 and 2004. They used three different measures of SRH – comparing self with previous self (a temporal comparison); comparing self with other people of the same age (an age-group comparison) and a no-comparison global rating (simply rated current health). They hypothesised that the age-group social comparison would show an increase as the sample increasingly engaged in downward social comparison (with those worse off) so as to enhance their self-rating; and that the temporal comparison would show worsened SRH.

People aged 16–44 years

Males 88.3%
Females 86.3%

People aged 45–64 years

Males 67.3%
Females 65.4%

People aged 65 and over

Males 43.1%
Females 36.%%

**Figure 1.4** Self-perceived health in the EU 2018: good and very good

*Source*: EU Eurostat (2020b).

In fact all three ratings worsened over time but the extent and rate of worsening varied: the global rating showed a steep decline over the 12 years; contrary to expectations, the age-group comparative ratings became more negative (in men but not those aged 65 on commencement); and while the self-comparative ratings became more negative, a ceiling effect is seen whereby, over time, participants became more likely to rate themselves as having stayed the same as previously.

Such findings demonstrate the important fact that the measures we use can influence the results we find and thus the interpretations we make. For example, a self-comparison measure is seen to plateau in the context of an ageing population, perhaps out of a feeling that 'my health cannot get any worse'. By scoring SRH as being 'same as the year previously', this could be misinterpreted as implying that health is better than expected given the passing of time and an assumption that actual health deteriorates over time. Such findings have relevance also for constructs other than self-rated health, for example. Chapter 5 ☛ describes how the comparator used in questions regarding drinking behaviour, or disease risk, can also change responses.

**Photo 1.4** Many activities can be enjoyed at any age.

*Source*: Radius Images/Design Pics/Alamy Images.

This chapter has described what is often meant by 'health'. In focusing on health, we have acknowledged that health is a continuum, not simply a dichotomy of sick versus healthy. Most of us will experience in our lifetime varying degrees of health and wellbeing, with periods of illness at one extreme and optimal wellness at the other. Some may never experience optimal wellness. 'Health refers to a state of being that is largely taken for granted' (Radley, 1994: 5) and is often only appreciated when lost through illness. In the final section of this chapter we want to introduce what is broadly considered as the discipline of health psychology. The final chapter of this book addresses careers in health psychology (Chapter 18 ☛).

# What is health psychology?

Before defining health psychology, let's first look at psychology as a discipline generally. Psychology can be defined as the scientific study of mental and behavioural functioning. Studying mental processes through behaviour is limited, however, in that not all behaviour, such as our thoughts, are observable. For many aspects of human behaviour we therefore have to rely on self-report, the problems of which are described elsewhere.

Psychology aims to describe, explain, predict and, where possible, intervene to control or modify behavioural and mental processes, from language, memory, attention and perception to emotions, social behaviour and health behaviour, to name just a few. The key to scientific methods employed by psychologists is the basic principle that the world may be known through observation = **empiricism**. Empirical methods go beyond speculation, inference and reasoning to actual and systematic analysis of data. Scientific research starts with a theory, which can be defined as a general set of assumptions about how things operate in the world. Theories can be vague and poorly defined (e.g. I have a theory about why sports science students generally sit together at the back of our psychology lectures) to very specific (e.g. sports science students sit at the back of lectures because they feel like 'outsiders' when placed with the large numbers of psychology majors). Psychologists scientifically test the validity of their hypotheses and theories. On an academic level this can increase understanding about a particular phenomenon, and on an applied level it can provide knowledge useful to the development of interventions.

Psychologists use scientific methods to investigate all kinds of behavioural and mental processes, from the response activity of a single nerve cell to the physical adjustments required in old age, and the research method employed will depend on what specific questions are being asked. You obviously would not use the same methods to establish the extent of language in a two-year-old as you would to identify which areas of the brain were activated during speech. This text highlights the methods most commonly employed by health psychologists: for example, the use of questionnaires, interviews and psychometric assessments (such as of personality).

## What connects psychology to health?

As already introduced, people have beliefs about health, are often emotional about it and have a behavioural role to play in maintaining it. As such, we can address questions such as:

- Why do some people behave in a healthy way when others do not? Is it all a matter of personality?
- Does a person who behaves in a healthy manner in one way, for example by choosing not to smoke, also behave healthily in other ways, for example, by attending dental screening? Are we rational and consistent beings?
- Does gender, age or socio-economic status affect health either directly or indirectly via their effects on other things such as lifestyle?
- Why do some people appear to get ill all the time while others stay healthy? What relationship is there between the mind and the body?
- What psychosocial and contextual factors can help a person adjust to, or recover from, illness and can these be targeted in psychologically informed interventions?

Health psychology integrates many cognitive, developmental and social theories and applies them solely to health, illness and healthcare. Health psychology was described at an early stage by Matarazzo as 'the aggregate of the specific educational, scientific and professional contribution of the discipline of psychology to the promotion and maintenance of health, the promotion and treatment of illness and related dysfunction' (1980: 815). This definition highlights the main goals of health psychology, i.e. we seek to develop understanding of biopsychosocial factors involved in:

- the promotion and maintenance of health;
- improving healthcare systems and health policy;
- the causes of illness: e.g. vulnerability/risk factors.
- the prevention and management of illness

Unlike some other domains of psychology (such as cognitive science), health psychology can be considered as an applied science, although not all health psychology research is predictive. For example, some research aims only to *quantify* (e.g. what percentage of school pupils drink under age?) or *describe* (e.g. what are the beliefs of under-age drinkers regarding the effects of alcohol?). Descriptive research ideally provides the foundation for the generation of more causal questions: e.g. do beliefs about alcohol in primary schoolchildren predict age of onset of under-age drinking? By simply measuring health beliefs and attitudes, we can begin to grapple with the

empiricism

arising from a school of thought that all knowledge can be obtained through experience issue of predictors (see Chapters 3–5 ☛). In other words we need to develop understanding first, then prediction, and then ideally we can develop evidence-based interventions that can be applied and evaluated in practice.

## Health psychology and other fields

Health psychology has grown out of many fields within the social sciences and it adopted and adapted models and theories originally found in social psychology, behaviourism, clinical psychology, cognitive psychology, etc. In fact you should also pick up an introductory psychology text and look at the learning, **motivation**, social, developmental and cognitive sections in more detail. Health psychology in Europe is, as in the USA and Australasia, linked with other health and social sciences (e.g. psychosomatic medicine, behavioural medicine, medical sociology and, increasingly, health/behavioural economics) and with medicine and allied therapeutic disciplines. Few academic or practitioner health psychologists work alone; most are involved in an array of inter- and multidisciplinary work and in fact this is increasingly valued and encouraged by our university employers and our research funders (see Chapter 18 ☛). In each of the above named disciplines dualist thinking regarding mind–body separation has been challenged, but each have differences in their theoretical underpinning (i.e. sociological, medical, psychological) and in the resulting methods of assessment, research and intervention suggested or employed.

### Psychosomatic medicine

Developed in the 1930s, this initially was the domain of now well-known psychoanalysts, e.g. Alexander, Freud, and offered an early challenge to biomedicine as discussed earlier. ‘Psycho-somatic’ refers to the fact that the mind and body are both involved in illness, and where an organic cause is not easily identified the mind may offer the trigger of a physical response that is detectable and measurable. In other words, mind and body act together. Early work asserted that a certain personality would lead to a certain disease (e.g. Alexander’s ‘ulcer-prone personality’; Freud’s ‘hysterical paralysis’), and while evidence of direct causality is limited, these developments in thinking certainly did set the groundwork for fascinating studies of physiological processes that may link personality type to disease (see Chapter 11’s ☛ discussion of hostility and heart disease associations, for example). Until the 1960s, psychosomatic research was predominantly psychoanalytical in nature, focusing on psychoanalytic interpretations of illness causation, such as asthma, ulcers or migraine being triggered by repressed emotions. However, one negative by-product of this work is that among those with a biomedical viewpoint, illnesses with no identifiable organic cause were often dismissed as nervous disorders or psychosomatic conditions for which medical treatment was often not forthcoming. Illnesses with no physical evidence are known as psychogenic (see Chapter 8 ☛ for a discussion of chronic pain which sometimes falls into such considerations, and Chapter 9 ☛ for discussion of medically unexplained symptoms).

Psychosomatic medicine today is more concerned with mixed psychological, social and biological/physiological explanations of illness i.e. illnesses are often viewed as ‘psychophysiological’. The increased acceptance during the 1970s that psychological factors can affect any physical condition led to the emergence of an integrated discipline known as behavioural medicine, and to health psychology itself.

### Behavioural medicine

This is essentially an interdisciplinary field drawing on a range of behavioural sciences, including psychology, sociology, health education, and behavioural economics, and applying them to medicine and medical conditions (Schwartz and Weiss, 1977). As its name suggests, behavioural principles (i.e. that behaviour results from learning through classical or **operant conditioning**) were applied to the evaluation of prevention and rehabilitation, as well as of treatment. In furthering the view that the mind had a direct link to the body (e.g. anxiety can raise blood pressure, fear can elevate heart rate), some of the therapies

**motivation**

memories, thoughts, experiences, needs and preferences that act together to influence (drive) the type, strength and persistence of our actions

**operant conditioning**

attributed to Skinner, this theory is based on the assumption that behaviour is directly influenced by its consequences (e.g. rewards, punishments, avoidance of negative outcomes) proposed, such as biofeedback (see Chapter 13 ☛) work on the principle of operant conditioning and feedback. Prevention however receives less attention within behavioural medicine than rehabilitation and treatment of illness, which highlights one of the key differences between it and health psychology.

Matarazzo distinguished between 'behavioural health' and 'behavioural medicine', with the former being more concerned with health enhancement and disease prevention rather than focusing on those with illness as behavioural medicine does. 'Behavioural health' is not however a stand-alone discipline but has been assimilated into others, including those areas of health psychology we describe in the following three chapters, i.e. behaviour and lifestyle factors associated with health and illness.

## Medical psychology

In the UK, medical psychologists would now tend to be termed health psychologists who do not dispute the biological basis of health and illness but who have adopted a more holistic model. In other parts of Europe, for example the Netherlands, the term 'medical psychologist' describes a professional working in a medical setting who has completed a psychology degree and Health Psychology Masters training (one or two years), followed by a two-year internship for generalist practitioner certification, or clinical psychology training (as for Health Psychology but adding a further four years to get full state specialist certification) (Soons and Denollet 2009). In the USA the term is used to describe a clinical psychologist who incorporates somatic (physical) medicine into their consideration of mental illness, and in some cases they can even prescribe medicines. Thus 'medical psychology' is a term more aligned to a profession than to a specific cognate discipline.

## Medical sociology

Medical sociology exemplifies the close relationship between psychology and sociology, with health and illness being considered in terms of the wider social, political and contextual factors that may influence individual experience. It takes a wider (macro) approach to the individual in that they are considered within family, kinship, culture. While health psychology also considers external influences on health and illness, it has traditionally focused more on the individual's cognitions/beliefs and responses to the external world and obviously takes a psychological rather than a sociological perspective. The growth over time of a more critical and reflective health psychology may make the boundaries between medical sociology and health psychology more blurred and certainly in our textbook we address the contextualisation of individual behaviour, thought and emotion in every chapter; however we still look to sociology more for wider sociopolitical considerations.

## Clinical psychology

Health psychology and health psychologists are often confused with clinical psychology and clinical psychologists as both are concerned with psychological explanations of human health and behaviour. At a basic level, clinical psychology has traditionally been concerned with mental health and the diagnosis and treatment of mental health problems (e.g. personality disorders, phobias, anxiety and depression, eating disorders). Clinical psychologists are typically practitioners working within the healthcare setting, delivering assessments, diagnoses and psychological interventions that are derived from behavioural and cognitive principles, e.g. CBT. While health psychology research may also be used to guide cognitive-behavioural interventions (see later chapters), and increasing health psychologists are employed in the health sector, the populations with whom we work are typically those experiencing physical health concerns or at risk of those via their behaviours. The professional practitioner status of our discipline differs across countries and you are referred to your national psychological associations for more information and also to Chapter 18 ☛ where we describe health psychology careers.

## Health psychology

Health psychology is fundamentally a discipline within the larger discipline of psychology: we are first and foremost psychologists. As mentioned earlier, health psychology emerged in the late 1970s and takes a biopsychosocial approach to health and illness. This means that it considers biological, social and psychological factors involved in the aetiology, prevention or treatment of physical illness, as well as in the promotion and maintenance of health. Health psychologists also need a basic (or good!) understanding of body systems and their function including that of the nervous system, endocrine system, immune system, respiratory and digestive systems (see Chapter 8 ☛).

Health psychology has developed over time, both academically and professionally, with different terminology and roles in different corners of the globe. Some health psychologists increasingly align themselves with public health to address issues such as immunisation, infectious disease control, epidemics, and implications for health education and promotion (see McManus, 2014, letter to *The Psychologist*); and others embrace *critical health psychology*, which addresses criticism that health psychology has been too individualistic in focus, at the expense of the social, although this is less valid now than when we produced our first textbook 15 years ago! To address early concerns raised by critical health psychology, we have incorporated throughout this textbook a consideration of wider influences on health, and on illness, such as culture, lifespan and socio-economic **variables**. Humans do not operate in a vacuum but are interacting social beings shaped, modelled and reinforced in their thoughts, behaviour and emotions by people close to them, by less known people, by politicians, by their culture, and even by the era in which they live. Consider, for example, women and work stress – this was not an issue in the 1900s, when society neither expected nor particularly supported women to work, whereas in the twenty-first century we have a whole new arena of women's health issues that in part may relate to the way women's roles have shifted in society. Where the biopsychosocial model was initially often treated by health psychologists as if the three components were simultaneous but separate influences (Crossley, 2000), research today acknowledges the interplay and integration between the biological, social and psychological, with the role of cultural and ethnicity influences at a more macro level advocated also (e.g. Suls and Rothman, 2004) although these are less consistently addressed. More recently, Lehman et al.'s (2017) dynamic biopsychosocial model of health has provided a more contextualised approach to health, with fuller consideration given to interpersonal dynamics and the passage of (historical and developmental) time than the typical biopsychosocial model taken from Engel (Engel, 1977). Borrowing concepts from theories such as Bronfenbrenner's ecological systems theory (1979; 1986), Lehman's model considers **microsystem** factors which are a person's immediate context of family, friends, colleagues, healthcare provider for example, **mesosystem** factors which refer to interpersonal interactions between microsystem components, for example the reciprocal influences between a person and their family or healthcare systems during illness experience (see Chapter 15 ☛), **macrosystem** factors, contextual factors such as healthcare policies, systems and access to them, sociocultural norms and shared values, and **exosystem** factors, such as the more indirect influences such as the role played by mass media in portraying a health condition (think of COVID-19, AIDS, liver failure) or the role played by medical training in the care subsequently received. This model acknowledges that the biological, psychological, social/interpersonal and contextual factors interact in a reciprocal and dynamic way with the salience or 'centrality' of factors changing over time as each or all change – for example, a person's illness beliefs may shift as biological aspects of an illness change or as they move from hospital to home, or from home to work, where different forms and systems of care are available.

Society (local, regional, national, global) and politics plays a significant role in the human experience of health and illness. There is a greater and growing acknowledgement of the rich diversity of cultures in the UK and the rest of Europe, and how variation in their beliefs and expectancies influence health and illness behaviour.

**variable**

(noun): something that can be measured or is reported and recorded as data, such as age, mood, smoking frequency or physical functioning

**microsystem**

a person's immediate direct contacts including family, friends, class mates or colleagues

**mesosystem**

where multiple aspects of a person's microsystem interconnect and act upon the individual, for example communications between a person's family member and a healthcare provider

**macrosystem**

a person's wider setting including socioeconomic, environmental and cultural factors that frame the structures and relationships between all other systems

**exosystem**

where individuals are affected by systems they are not part of, for example a partner's inflexible workplace policies, media coverage of a health issue

Through review, critique and reflection, the still relatively new discipline of health psychology has developed and strengthened. As potential health psychologists of the future, readers should be aware of the risks of complacency and the importance of reflection and critique!

The professional title 'health psychologist' is recognised now in many countries, including, for example, the British Psychological Society and the Health Professions Council UK, The American and Australian Psychological Societies. In the UK we distinguish between an HPC registered Health Psychologist Practitioner with certified competencies in ethical practice, research, teaching, consultancy and interventions, and who may be employed within our National Health Service within the pain service, or in rehabilitation for example, and an Academic Health Psychologist who is also educated to Doctoral level but whose work is generally within higher education and confined to teaching and research (often in collaboration with health professional practitioners). Academic Health Psychologists would not be eligible to work directly in practice with patients' but may consult with those practitioners to develop effective interventions or to evaluate them. Interested readers should refer to their own professional bodies for current role descriptors and career opportunities.

In conclusion, this textbook considers personal, cultural and social perspectives on health and illness in an integrated manner and is aligned with mainstream psychological thinking. Moving from theory, through robust and methodologically rigorous research, we highlight the central goal of developing a theoretical and empirical understanding of human health and illness. Only then can we apply that understanding to the development of interventions in healthcare practice or to the communication of science to those tasked with shaping health policy. For a discipline to continue to evolve, ongoing methodological and theoretical review, critque and development are important and so we point out the limitations of some general assumptions of the field and of some study findings as we proceed. It is important that current readers hear what I often say to my own students – 'just because it is published doesn't mean it is perfect', and while introductory textbooks seek to summarise the current state of knowledge in an area, they do so in a relatively superficial way. Readers need also to pursue some of the many references to empirical studies cited. As a starting point, see de Bruin and Johnston's commentary (de Bruijn and Johnston, 2012), which offered a timely review of research methods within health psychology and which led to stimulating and ongoing reflection and debate within our European Health Psychology Society.

## SUMMARY

This chapter has introduced key areas of interest to health psychologists, including:

- What is health?
  - Health appears to consist broadly of domains of 'having', 'doing' and 'being', where health is a reserve, an absence of illness, a state of psychological and physical wellbeing; is evident in the ability to perform physical acts, as fitness, and is generally something that is taken for granted until it is challenged by illness.
- How have health and illness been viewed over time?
  - Views of health have shifted from fairly holistic views, where mind and body interact, to more dualist views, where the mind and body were thought to act independently of one another. This has shifted back towards holism, with the medical model being challenged by a more biopsychosocial approach.
- What influence does culture have on how health is perceived?
  - Culture can be grounded in collective or individualistic orientations, and these will influence explanations for health and illness as well as the behaviour of those within the culture.
- What influence might lifespan play on how health is perceived?
  - Children can explain health and illness in complex and multidimensional terms; and human expectations of health change over our lifespan as a function of experience as well as of cognitive development.
- What is health psychology?
  - Health psychology is the study of health, illness and healthcare practices (professional and personal).
  - Health psychology aims to understand, explain and ideally predict health and illness behaviour in order that effective interventions can be developed to reduce the physical and emotional costs of risky behaviour and illness.
  - Health psychology offers a holistic but fundamentally psychological approach to issues in health, illness and healthcare.

## Further reading

S. Kitayama and D. Cohen (eds) (2007). *Handbook of Cultural Psychology*. New York: Guilford Press.

This 30-chapter text has become a leader and a landmark text for anyone interested in the role culture plays at all levels in terms of perceiving self and others, and in terms of cognition, emotion and motivation, and development. While not focusing on health specifically, it is worth a look.

Turner-Cobb, J. (2014). *Child Health Psychology*. London: Sage.

This book goes a significant way towards filling a gap in the market of health psychology textbooks in that it focuses specifically on psychosocial and developmental aspects of child health and illness, including, as pertinent to this chapter, discussion of the health concept.

The British Psychology website is useful for defining health psychology as a discipline and as a profession in the UK (see also Chapter 18 (☛):

http://www.bps.org.uk/careers-in-psychology

The European Health Psychology Society website provides access to useful information about research across Europe, health psychology in practice, and access to the European health Psychologist Bulletin:

http://www.ehps.net/index.php?option=com_content&view=article&id=1&Itemid=118

Those interested in health psychology as applied to public health issues may find this organisation useful; they also address behavioural science more broadly:

https://www.bsphn.org.uk/

If you have an interest in global health issues and sustainable development goals, this site is worth a look at and is regularly updated.

https://sdgs.un.org/publications/transforming-our-world-2030-agenda-sustainable-development-17981

# Chapter 2

# Health differences and inequalities

## Learning outcomes

By the end of this chapter, you should have an understanding of:

- the impact of poverty on health
- causes of variations in health between and within countries
- the impact of socio-economic deprivation on health and theories of why this occurs
- the relationship between work stress, unemployment and health
- the health impact of having a minority status in society
- the impact of gender on health

## Viruses cause ill health throughout the world – but not always in the way you think

Governments across the world are trying to make us healthier. We are urged to eat healthily, exercise and avoid drinking too much alcohol. But is this drive to healthy behaviours hiding an insidious fact – and one governments would like us to ignore? Perhaps the most important contributor to our health is not what we do, but where in society we are. A job is better for your health than no job at all. But better jobs are better for your health. People who live in deprived areas are likely to live 10 or more years less than those in less deprived areas. Women are more likely to experience work stress and its associated ill health than men. People in ethnic minorities may experience poorer working conditions and stress related to prejudice. They have also proven more susceptible to diseases evident throughout society such as COVID-19. These factors are easy to identify – difficult to change. And at a time of economic stringency, which many industrialised countries are now facing, health disparities due to work and social pressures, as well as difficult economic conditions, are likely to increase rather than decrease. The health as well as the wealth of nations may well suffer in the next few years as a result of a range of government policies and the economic pressures resulting from events such as the COVID-19 pandemic.

## Chapter outline

This chapter considers differences in health status that arise not as a result of individual behaviour but from the social context in which we live. Among other things, it considers why better-off people tend to live longer than those who are less well off, why women generally live longer than men, and why people from ethnic minorities are more likely to die earlier than those from majority populations. The greatest killer in the world is poverty, which is associated with poor nutrition, unhealthy water supplies, poor healthcare, and other factors that directly influence health. Among people who do not experience such poverty, more subtle social and psychological factors influence health. Men's health, for example, may be influenced by a general reluctance to seek medical help following the onset of illness. People who are economically deprived may experience poorer health because of problems of accessing healthcare, and greater levels of stress than the more economically well off. This chapter examines how social and psychological processes differentially influence health as a result of **socio-economic status (SES)**, ethnicity, gender and working environment.

# Health differentials

Where we live, as well as our social and economic circumstances, can have a profound effect on our health. The biomedical model of health and ill-health has typically focused on biological factors such cholesterol and blood pressure influences on health. Psychological perspectives have generally focused on health behaviours such as exercise and diet, and factors that may influence them, including attitudes, perceived norms, and self-efficacy (see Chapters 3, 4, and 11 (☛). However, there is a strong body of evidence that environmental and social factors may have an equal, if not greater, influence on our health. The better-off tend to live longer than the less well off. People who occupy minority roles in society as a result of ethnic or other factors may experience more illness or die earlier than the majority population. Even findings that women live longer than men now appear to have psychosocial as well as biological explanations.

This chapter considers how and why people experience differences in health and longevity as a result of their socio-economic status (SES), ethnicity, gender, and working conditions. It considers each factor separately, although in reality each of them may be intimately intertwined. People with relatively low incomes, for example, may engage in more health-damaging behaviours and also have jobs or experience work practices that increase their risk of disease. Accordingly, although this chapter attempts to identify the specific health gains or risks associated with different social contexts, it should be remembered that many individuals face multiple advantages or disadvantages as a result of occupying several social contexts.

## Evidence of health differentials

There are clear **health differentials** between countries. As can be seen in Table 2.1, all the countries whose

**socio-economic status**
a measure of the social class of an individual; different measures use different indicators, including income, job type or years of education; higher status implies a higher salary or higher job status

**health differential**
a term used to denote differences in health status and life expectancy across different groups

**Table 2.1** Life expectancy, by gender, in years for the highest and lowest ranked countries by World Health Review, 2019

| Top 5 | Male | Female |
|---|---|---|
| Hong Kong | 81.88 | 87.66 |
| Japan | 81.41 | 87.59 |
| Macau | 81.20 | 87.1 |
| Switzerland | 81.76 | 85.53 |
| Singapore | 81.41 | 85.65 |
| Bottom 5 | | |
| Ivory Coast | 53.39 | 56.37 |
| Nigeria | 53.72 | 55.39 |
| Central African Republic | 51.83 | 55.86 |
| Chad | 52.40 | 54.89 |
| Sierra Leone | 52.05 | 53.37 |

*Source*: http://worldpopulationreview.com/countries/life-expectancy/.

populations experience the shortest life expectancy are in Africa. Countries with the best health are scattered around the world; although the top five are now, with only one exception, in relatively rich Asian countries. Given these data, one may expect that populations of rich nations simply live longer than those of the poorer nations. This is generally, but not universally, true. The USA, for example, fared rather badly in the 2019 World Population rankings, at only 45th place (one below Lebanon), with an overall life expectancy of 79.7 years. Clearly the wealth of a country is not the sole indicator of the health of its citizens.

Despite recent health gains (https://childmortality.org/), nearly one-third of deaths in developing countries occur before the age of 5 years while a further third of deaths occur before the age of 65 years. This contrasts with the average two-thirds of deaths that occur after the age of 65 years within the industrialised countries. The factors that contribute to these differences are economic, environmental and social. People in many developing countries may experience significant health risks; from lack of safe water, poor sanitation, inadequate diet, indoor smoke from solid fuels, and poor access to healthcare.

The WHO has estimated that poverty causes around 12 million deaths each year in children under the age of 5 living in the developing world, with the most common causes of death being diarrhoea, dysentery and **lower respiratory tract infections** (https://afro.who.int/health-topics/poverty). Major killers among the adult population include being underweight, tuberculosis and malaria. This high risk for death through infection contrasts markedly with the industrialised nations, where the key causes of death are chronic disease and abuse of drugs such as tobacco and alcohol.

One particular issue still facing many countries in Africa is that of HIV infection and AIDS. In sub-Saharan Africa, an estimated 19.6 million people, 6.8 per cent of the population, were living with HIV in 2017 (Avert, 2021). Southern Africa was the worst affected region and is considered to be the 'epicentre' of the global HIV epidemic. Here, Swaziland had the highest HIV rate of infection in the world, with 27.2 per cent of its population living with HIV; South Africa had a lower **prevalence**, but as a much larger country had nearly 9 million people living with the virus. By comparison, the prevalence of HIV in West and East Africa is considered 'low' to 'moderate' averaging a 1.9 per cent prevalence rate across its various countries, while the rate in the UK in the same period was 0.017 per cent.

## Even the 'haves' experience health differentials

While the industrialised world may not have the profound levels of poverty and illness found in the developing world, there are gradients of wealth within these countries, and differentials in health that match them. The richer people within most industrialised countries are likely to live longer than the less well-off and be healthier while alive: see Hosseinpoor et al.'s (2012) confirmatory data across 57 countries. One example of this can be found in data reported by Rasulo et al. (2007). They calculated the expected 'healthy life expectancy' of individuals living in 8,797 specified areas of the UK and the level of social deprivation of each area using a measure of deprivation

**lower respiratory tract infection**

infection of the parts of the respiratory system including the larynx, trachea, bronchi and lungs

**prevalence**

the percentage or total number of people to have a disease in a given population at any one time; contrasts with incidence, which is the number or percentage of people who develop a particular disease within a particular time frame – prevalence is the number or percentage of existing cases, incidence is the number of new cases known as the Carstairs's deprivation score. This measures levels of household overcrowding, male unemployment, economic deprivation, and car ownership. They then calculated how long people were expected to live in good health across the varying levels of deprivation and found a linear relationship between deprivation scores and expected 'healthy life expectancy' (see Figure 2.1). They reported a staggering 13.2-year difference between those in the least and most deprived areas.

Even more worryingly, similar data across England and Wales between 2012/4 and 2015/7 revealed increased inequalities over this time (Office for National Statistics 2019). Typical findings included evidence that women living in the most deprived areas of Wales lived up to 11 years in a poorer state of health than their counterparts in the least deprived areas. In England, men resident in the least deprived areas could expect 13.3 years of good health from 65 years of age, but only 5.8 years if they lived in the most deprived areas. Despite these stark statistics, it is important to note that the relationship between SES and health is *linear*, indicating not just that the very poor die earlier than the very rich: instead, it indicates that quite modest differences in wealth can influence health throughout society. Finally, it should be noted that while most diseases linked to SES and premature mortality or morbidity are chronic 'lifestyle' diseases, being economically deprived can also have an adverse influence following a range of more acute health challenges, including risk of death from COVID-19 (e.g., Williamson et al., 2020).

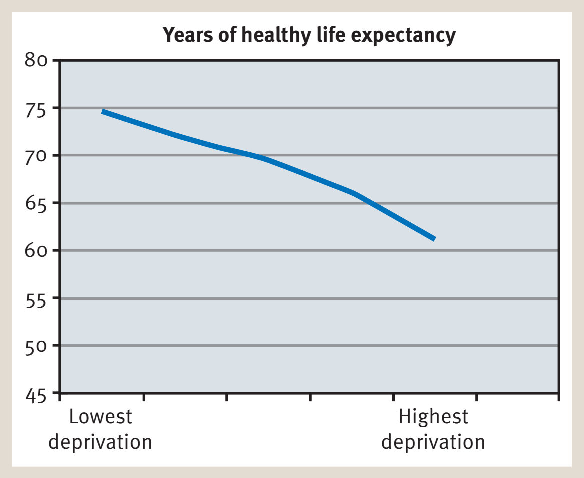

**Figure 2.1** Years of healthy life expectancy according to Carstair's deprivation scores in the UK

*Source*: From 'Inequalities in health expectancies in England and Wales: small area analysis from 2001 Census', Health Statistics Quarterly, 34 (Rasulo, D., Bajekal, M. and Yar, M. 2007).

## Explanations of socio-economic health inequalities

A number of explanations for health inequalities within industrialised countries have been proposed, some of which attribute responsibility to the individual. Others suggest that factors related to occupying different socio-economic groups may directly impact on health. But the first issue that has to be addressed is the causal direction between SES and health. Does SES influence health, or does health influence SES?

### Social causation versus social drift

Explanation for socio-economic health differentials pits a social explanation against a more individual one. The first, the social causation model, suggests that low SES 'causes' health problems – that is, there is something about occupying a low socio-economic group that adversely influences the health of individuals. The opposing view, the social drift model, suggests that when an individual develops a health problem, they may be unable to maintain or obtain the quality of job required to maintain their standard of living. They therefore drift down the socio-economic scale: that is, health problems 'cause' low SES.

Longitudinal studies have provided evidence relevant to these hypotheses. These typically identify a representative population of several thousand healthy individuals who are then followed over a number of years to see what diseases they develop and from what causes they die. Differences in measures taken at baseline between those who do and do not develop disease indicate likely risk factors for disease: people who die of cancer, for example, are more likely to have smoked at baseline than those who did not, suggesting smoking contributes to risk for developing cancer.

Each of the studies using this form of analysis has found that baseline measures of SES predict subsequent health status, while health status is less predictive of SES or a lowering of SES (e.g. Pulford et al., 2018). Other data supporting the social causation model show that as people move from employment to unemployment or insecure jobs as a result of factors unrelated to their health, younger and middle-aged adults may experience deteriorating health (Van Aerden, Gadeyne and Vanroelen, 2017), while older individuals experience higher mortality rates (Montgomery et al., 2013). Accordingly, while there may be some modest downward drift due to ill-health, SES is generally seen as a cause of differences in health status rather than a consequence.

Such inequalities may even be embedded in childhood. There is an emerging literature indicating childhood factors are equally as important as, if not more important than, concurrent factors in determining health. This may be due to the early establishment of difficult to change factors linked to low SES, including childhood obesity, that result in long-term metabolic problems such as diabetes (Tamayo, Christian and Rathmann, 2010). It may be even more fundamental. Austin et al. (2018) found early life SES disadvantage directly predicted measures of cellular ageing, with no mediation through concurrent SES or health-related behaviours, while Loucks et al. (2016) found that changes in gene expression related to obesity during childhood were directly related to mid-life body mass index. It seems that at least some risk profiles established in childhood may be relatively immutable over time.

## Different health behaviours

We identified in Chapter 1 ☛ how a number of behaviours influence our health. With this in mind, one obvious potential explanation for the higher levels of ill-health and **premature mortality** among people in the lower socio-economic groups is that they engage in more health-damaging and less health-promoting behaviours than those in the higher socio-economic groups. This does seem to be the case. People in lower socio-economic groups in industrialised countries tend to smoke and drink more alcohol, eat a less healthy diet and take less leisure exercise than the better-off (e.g. Casetta et al., 2017).

However, there is consistent evidence that while differences in health-related behaviours account for some of the socio-economic differences in health, they do not provide the full story. In a study of over 8,000 US older men and women, for example, Nandi et al. (2014) found that smoking, alcohol consumption and low levels of physical inactivity explained 68 per cent of the variance in deaths over a 10-year period. The rest was accounted for by SES. Interestingly, the influence of SES appears to vary across populations. Stringhini et al. (2011) found that health behaviours attenuated the association between SES and mortality in a UK population by 75 per cent. In a similar mainland European population, they reported the degree of attenuation averaged only 19 per cent.

**premature mortality**

death before the age it is normally expected. Usually set at deaths under the age of 65 years

What is perhaps worth considering here is *why* people in the lower socio-economic groups engage in more health-compromising behaviours. It does not appear to be the result of lack of knowledge (Narevic and Schoenberg, 2002). Rather, it may be a deliberate choice based on a calculation of the costs and benefits of such behaviours. These may include smoking as a means of coping with stress (e.g., Kobayashi and Kondo, 2019) to more subtle factors such as threatened loss of social contacts should an individual quit smoking (Hitchman et al., 2014). Similarly, Wood et al. (2010) found that many working-class mothers were aware of government guidelines on healthy eating, but this knowledge was often superficial and only formed part of their decision making in relation to eating. Priority in food choice was often based on taste, being filling, hot, and appetite-satisfying. Eating unhealthy foods was justified in various ways, and many mothers considered their meals acted as a form of emotional support that could improve other aspects of family wellbeing. The type of health-behaviour choices we make, and in some cases the availability of such choices may be strongly influenced by the social context in which we live.

## Access to healthcare

Access to healthcare is likely to differ according to the healthcare system with which the individual is attempting to interact. Many studies of this phenomenon, for example, have been conducted in the USA, where different healthcare systems operate across the social divide. Here, the Affordable Care Act (‘Obama Care’) improved many Americans’ access to healthcare; but very real differences in access and quality of care remain (Dickman, Himmelstein and Woolhandler, 2017).

By contrast, in the UK where the economic barriers to healthcare are less obvious than in the USA, people in lower socio-economic groups typically access healthcare more frequently than those in the higher SES groups, suggesting that no such economic division is found in the UK. Unfortunately, these data do not address whether the increased use of healthcare resources is sufficient to counter the additional levels of poor health associated with low economic status. What evidence there is suggests this is not the case. A report by Audit Scotland (2012), for example, highlighted findings that patients from deprived areas in Scotland received more than 20 per cent fewer cardiology treatments than would be predicted by rates of disease while those from the least deprived areas received over 60 per cent more treatments than would be predicted. Public Health England (2017) subsequently reported similar problems in health and social care among deprived areas of England.

As well as the provision of services, a range of subtle factors may contribute to differences in healthcare. People living in rural areas may have poorer access to healthcare or make choices based on the difficulties of travel to available medical treatment. Nelson, Bennett and Rance (2019), for example, found that men living in rural areas of Wales were more likely to opt for a '**watch and wait**' choice rather than active treatment such as radiotherapy for their prostate cancer than those in urban centres. These choices reflected the difficulties of repeated long journeys to hospitals providing radiotherapy necessary for this form of treatment. Similar decisions may be involved in both clinician and patient decisions in relation to a range of other treatments such as entry into cardiac rehabilitation programmes (see Chapter 8 ☛; e.g., Kachur et al., 2019).

Also relevant are peoples' attitudes to healthcare or their cultural beliefs. People from lower socio-economic groups may be less likely to seek appropriate medical care even when it is available (Wamala et al., 2007). Muslim women, for example, may be unwilling to access healthcare provided by male doctors and lack appropriate medical care where there is a shortage of female doctors (see discussion later in the chapter). Finally, even in contexts where treatment may be available without prescription, there may be inequalities in access. In the USA, for example, Bernstein et al. (2009) found that nicotine replacement therapy, a central element of any smoking cessation programme (see Chapter 6 ☛), was less available and more expensive in pharmacies in the poorer suburbs of New York than the more affluent ones. Cigarettes were equally accessible throughout the city.

### WATCH AND WAIT

The treatment of prostate cancer is often one of equipoise (see Chapter 10 ☛) with options of 'watch and wait' to identify if and when more active treatment is necessary, such as radiotherapy or surgery; the cancer is usually slow developing, so watch and wait can be a viable and safe treatment choice.

## Environmental factors

A third explanation for differences in health across social groups suggests that people in lower socio-economic groups are exposed to more health-damaging environments, including working in dangerous settings such as building sites, and have more accidents than those in the higher socio-economic groups throughout their working life. In addition, they may experience home conditions of low-quality housing, dampness and higher levels of air pollution than those in the higher socio-economic groups (World Health Organization, 2010). The economically less well-off are likely to live closer to main roads carrying high levels of traffic, airports, polluting industry, rubbish dumps, and power stations. These risks may be particularly problematic for children as a consequence of their physical status and their chronic exposure to such pollutants. Schools tend to be close to children's homes, so if a child lives in a polluted environment, they are also likely to experience this adverse condition at school. Excessive exposure to adverse environments may interact with poor health behaviours and health status in a multiplicative risk to health (WHO, 2010).

Environmental factors may also work through social and psychological pathways. Distance from exercise facilities, poor traffic safety, or poor environmental conditions may reduce levels of exercise, including walking to school (Panter et al., 2010), among both children and adults (e.g. Page et al., 2010). The most commonly reported neighbourhood barriers to healthy weight control reported by Jilcott Pitts et al. (2015) included not enough bicycle lanes, pavements, or affordable places to exercise; too much crime; and low availability of pre-prepared healthy meals combined with high access to fast food outlets. Higher levels of perceived barriers to exercise were associated with higher BMI. Healthy foodstuffs remain difficult to access by many poor Americans, while closer access to poor quality food in convenience stores has been linked to a range of unhealthy lifestyle choices (Sharkey et al., 2013).

A second pathway may be a direct consequence of poor living conditions. Both adults and children living in poor housing, for example, are more likely to suffer from a range of conditions including poor respiratory health and asthma (e.g. Baker et al., 2016), which may be mitigated to some extent by improvements to the fabric of the houses (Thomson et al., 2013).

The impact of housing may not simply be physical, however. One example of this can be found in the relationship between ownership or otherwise of peoples' homes. Simply put; tenants report higher rates of long-term illness than owner-occupiers. Woodward et al. (2003), for example, found that after adjusting for age, male renters were one-and-a-half times more at risk of developing **coronary heart disease (CHD)** (see Chapter 8 ☛) than male owner-occupiers; women renters were over twice as likely to develop CHD as their owner-occupier counterparts. More fundamentally, Clair and Hughes (2019) found that levels of **C-reactive protein** (a marker of immune activation associated with high levels of stress and infection) were higher in renters than home-owners. Similarly, those in detached houses had lower levels of C-reactive protein than those living in semi-detached, terrace houses or flats.

Some of the reasons for these differences may be indirect and lie in other factors linked to renting by people in difficult economic circumstances. Sandel et al. (2018), for example, found a range of factors, including stress associated with multiple moves and rental arrears, impacted on the health of both children in a household. Very low-income renters may also experience food insecurity; itself a stress factor and contributor to poor personal and child health (Frank et al., 2006). However, a further potential pathway raises some interesting psychological issues. MacIntyre and Ellaway (1998) found a range of mental and physical health measures to be significantly associated with housing tenure even after controlling for the quality of housing, and the age, sex, income and self-esteem of their occupiers. They interpreted these data to suggest that the type of tenure itself is directly associated with health. They suggested that the degree of control we have over our living environment may influence mood, levels of stress, and perceived control over a wider set of health behaviours; all of which may contribute to ill health. In addition, negative social comparisons, considering one's own house as worse than others' houses, appear to have a direct effect on self-esteem, anxiety, and depression, which may in turn influence health (Ellaway et al., 2004).

**coronary heart disease**

a narrowing of the blood vessels that supply blood and oxygen to the heart; results from a build-up of fatty material and plaque (atherosclerosis); can result in angina or myocardial infarction

**C-reactive protein**

a marker of immune activation associated with high levels of stress and infection

## Stress, SES and health

The implication of the previous section is that poor housing leads to stress, which in turn leads to ill-health. This argument can be widened to suggest that differences in stress experienced as a result of a variety of factors may combine to contribute to differences in health across the social groups. This seems a reasonable hypothesis, as we know that people in lower SES groups experience more stress than their more affluent counterparts (e.g. Marmot et al,. 1997), have less personal resources to help them cope with them (Finkelstein et al., 2007), and that stress can adversely impact on health (see Chapter 11 ☛). Some of the stresses and restricted life opportunities experienced by people in lower socio-economic groups include:

- *Childhood*: family instability, overcrowding, poor diet, restricted educational opportunities;
- *Adolescenc*e: family strife, exposure to others' and own smoking, leaving school with poor qualifications, unemployment or low-paid and insecure jobs;
- *Adulthood*: working in hazardous conditions, financial insecurity, periods of unemployment, low levels of control over work or home life, negative social interactions;
- *Older age*: no or small occupational pension, inadequate heating and/or food.

Wilkinson (1990) took the stress hypothesis one stage further. He compared data on income distribution and life expectancy across nine Western countries and found that, while the overall wealth of each country was not associated with life expectancy, the income *distribution* across the various social groups (i.e., the size of the economic gap between the rich and poor) within each country was. The correlation between the two variables was a remarkable 0.86: the higher the income disparity across the population, the worse its overall health.

In his explanation of these phenomena, Wilkinson suggested a 'hierarchy-health hypothesis'. According to Wilkinson, awareness of being low in the hierarchy and of one's relative lack of resources is itself stressful and may cause negative emotional responses, regardless of more objective measures of wealth or status. Support for this approach can be derived from the findings of Singh-Manoux, Marmot and Adler (2005), who found subjective SES was a better predictor of health than actual measured SES.

Wilkinson later shifted this explanation to suggest that wealth disparities were associated with lower levels of social cohesion and **social capital** in lower SES groups (Wilkinson and Pickett, 2010). Low social capital is associated with both individual distrust and dissatisfaction, and social factors such as high levels of crime. It involves not feeling safe in the community in which you live: a perception that is inherently stressful. In one study of this phenomenon, Scheffler et al. (2008) examined the association between social capital and the incidence of acute coronary events in different areas of California and found that higher levels of community-level social capital were associated with an 11 per cent lower rate of coronary events. This protective effect was largely confined to people whose household income was below $54,000 (around the 60th US income percentile). In reality, while low social capital is associated with low SES, it may exert an independent influence on health. Aida et al. (2013), for example, found both SES and social capital to be related and independent influences on health.

A further factor related to social capital that may covary with SES is the social support available to the individual. A large number of positive social relationships and few conflictual ones may buffer individuals against the adverse effects of the stress associated with low economic resources. Conversely, a poor social support system may increase risk for disease (Barth et al., 2010). Sadly, the potentially protective effect of good social support may be less available than it was previously. In

social capital

feelings of social cohesion, solidarity and trust in one's neighbours

**Photo 2.1** Just kids hanging around. But how will their life circumstances affect their health (and perhaps that of others)?

*Source*: LeoPatrizi/E+/Getty Images.

contrast to research conducted in the 1950s, people in the higher social groups now appear to have more social support than those in the lower social groups, particularly where low socio-economic status is combined with high levels of social mobility and frequent changes of address (Chaix et al., 2007).

This social capital/support model is compatible with theorising of Matthews and Gallo (2011) who noted that stress may well contribute to health inequalities but found an even stronger relationship between poor health and what they termed lack of 'reserve capacity'; the capacity to cope with this stress (to which both social capital and social support would contribute). They noted, for example, in one analysis conducted by Matthews et al. (2008) that low levels of education (and hence, SES), were related to **metabolic syndrome** through a pathway involving low levels of reserve capacity (defined as low levels of optimism, self-esteem, and social support). Thus, they argued, risk for disease may be associated with a lack of coping resources rather than stress *per se*.

**metabolic syndrome**

the presence of three of: central obesity, high blood pressure, high blood sugar, high serum triglycerides, low serum high-density lipoprotein. These increase risk of cardiovascular disease and type 2 diabetes

## RESEARCH FOCUS

### Does ethnicity influence risk and impact of Covid-19?

Lassale, C., Gaye, B., Hamer, M. et al. (2020). Ethnic disparities in hospitalisation for COVID-19 in England: the role of socioeconomic factors, mental health, and inflammatory and pro-inflammatory factors in a community-based cohort study. *Brain, Behavior, and Immunity*, 88: 44–49.

The authors note that among UK and US patients known to have COVID-19, some ethnic groups appear to have the highest risk of needing intensive care and are the most likely to die from the infection. Some of this increased risk may be attributed to neighbourhood deprivation and comorbidity, but other causes need to be considered. Issues to be considered include overcrowded living, occupations involving contact with the public, mental health, and lifestyle factors associated with pro-inflammatory conditions and chronic disease. The chronic stress of occupying minority or low socioeconomic status may also result in impaired immunological functioning and contribute to risk.

### Method

Data were obtained from the database of a massive prospective study known as UK Biobank, which is following a cohort of over half a million people aged between 40 and 69 years across the UK. People in the cohort were considered to have been hospitalised with COVID-19 if they had a positive COVID-19 swab test between the 16 March and 26 April, when testing was largely restricted to in-hospital cases. Accordingly, a positive test result was seen as indicating the presence of severe COVID-19 infection. The study only included participants living in England, as neither Wales nor Scotland had these data.

### Measures

- *Ethnicity*: this categorised people into one of six categories: White, Mixed, Asian or Asian British, Black or Black British, Chinese, and Other.
- *Socioeconomic measures*: included highest education level, household income, occupation, and Townsend Index of Area Deprivation.
- *Lifestyle measures*: physical activity, smoking and alcohol consumption measured by questionnaire. Activity measured by the International Physical Activity Questionnaire, measuring duration of various levels of activity. Results categorised as inactive, somewhat active below guidelines, and meeting activity guidelines (>150 min/week moderate to vigorous; >75 mins vigorous activity).

*(continued)*

- *Comorbidities*: Body Mass Index calculated from weight and height. Self-report of other conditions/ illnesses. Mental health measured by the Patient Health Questionnaire, and verbal numerical reasoning task used to measure cognitive function.
- *Biomarkers*: blood samples measured C-reactive protein (measure of inflammation), haemoglobin, HbA1c (test of diabetes) (see Chapter 8 ☛) and total and high density lipoprotein (HDL) (see Chapter 8 ☛).

## Statistical analysis

Comparisons were made between hospitalised and non-hospitalised patients via t-tests and Chi-squared.

Logistic regression was used to estimate odds ratios (ORs) of associations between ethnicity and hospitalisation for COVID-19. To quantify the contribution of factors to the ethnic differences, they first ran a ‘comparator model’ where ORs were adjusted for age and sex. They subsequently fitted five models with additional covariates: (i) socio-economic, (ii) lifestyle, (iii) comorbidities, (iv) biomarkers, and (v) all covariates. The percentage change following each additional covariate was reported.

## Results

The analysis was conducted on 340,966 individuals, of which 640 were COVID-19 cases. Characteristics of those hospitalised with COVID-19 in comparison with the non-hospitalised group were older, less likely to be female, lower education, living in deprived neighbourhoods, less active and higher smoking, higher co-morbidities in terms of illness and markers of poor health (greater BMI, HbA1c levels, total cholesterol, lower HDL-cholesterol and lung function. In comparison to White participants, there were three times more Blacks and two times more Asians hospitalised with COVID-19. Table 1 provides a summary of some key findings).

## Modelling risk

Regression analysis showed that compared to White participants, people from a Black ethnic background were at over four times the risk of being hospitalised for COVID-19 than their age and gender matched White equivalents (odds ratio [OR]: 4.32; 95% confidence intervals [CI] 3.00–6.23). Those of Asian origin were at double the risk (OR: 2.12; 95% CI: 1.37, 3.28). The importance of covariates in predicting risk were measured by adding them in the sequence described above. The results are reported in terms of the degree of attenuation (e.g., how much their inclusion reduced risk of hospitalisation) of each risk factor in each ethnic group. They show the highest risk of hospitalisation was in the Black population followed by Asians and ‘Others’. This risk was reduced when taking into account SES, with reductions in risk of 24.5% for Blacks, 31.9.3% for Asians, and 30.0% for Others. Addition of lifestyle, comorbidities, and biomarkers of disease reduced risk a further 33.0% for Blacks, 52.2% for Asians and 43.0% for Others compared to the base model.

## Discussion

These data show increased risk of hospitalisation for COVID-19 among the non-White population of England. The regression analysis showed that differences in risk were at least partially attributable to a range of co-variates including lifestyle, existing health differences and SES. Nevertheless, these differences remained significant for each group, and in particular Black people. Clearly, there are psychosocial factors that predict risk, which although not directly found in this study may contribute to the findings. These include the higher prevalence of public-facing jobs held by people in ethnic minorities and living in more crowded housing (both leading to lower social distancing). Lifestyle factors may also contribute to risk, while poorer mental health and inflammation also carry risk. The latter may be exacerbated by factors such as racism. Future research needs to identify factors that influence risk at a more molar level, digging down into *how* being in a lower socio-economic group confers risk and to identify the factors beyond those identified in this study which contribute to the remaining differences.

| | Not hospitalised | Hospitalised | p-value |
|---|---|---|---|
| Number | 427,594 | 900 | |
| Ethnicity (%) | | | <0.001 |
| Black | 1.8 | 6.0 | |
| Asian | 2.2 | 5.1 | |
| Other | 1.9 | 3.1 | |
| White | 94.1 | 85.8 | |
| Women (%) | 55.0 | 44.4 | <0.001 |
| Age, years (mean, SD) | 56.4 (8.1) | 57.2 (9.0) | 0.001 |
| | *Per cent* | | |
| Higher education | 32.6 | 26.0 | 0.001 |
| Household ≥ 4 people | 19.3 | 21.8 | 0.004 |
| Neighbourhood deprivation highest quintile | 19.6 | 33.0 | <0.001 |
| Physical activity | | | |
| Inactive | 18.2 | 26.3 | <0.001 |
| Alcohol intake | | | <0.001 |
| Never/rarely | 31.4 | 41.7 | |
| Heavy drinking | 32.7 | 29.8 | |
| Cigarette smoking | | | <0.001 |
| Never | 55.4 | 46.7 | |
| Current | 10.0 | 11.4 | |
| Hypertension | 58.0 | 65.8 | <0.001 |
| Diabetes | 5.0 | 9.9 | <0.001 |
| Cardiovascular disease | 5.3 | 10.3 | <0.001 |
| Chronic bronchitis | 1.4 | 3.1 | <0.001 |
| Psychological distress (PHQ4 ≥ 3) | 23.7 | 28.6 | 0.001 |
| | *Mean (SD)* | | |
| BMI, kg/m$^2$ | 27.4 (4.8) | 29.1 (5.4) | <0.001 |
| C-reactive protein (mg/L) | 2.51 (4.17) | 3.50 (6.39) | <0.001 |
| HbA1c (mmol/mol) | 36.0 (6.6) | 38.1 (8.9) | <0.001 |
| Cholesterol (mmol/L) | 5.70 (1.14) | 5.43 (1.22) | <0.001 |
| HDL-cholesterol (mmol/L) | 1.45 (0.38) | 1.32 (0.33) | <0.001 |
| Lung function: Forced expiratory volume | 2.82 (0.8) | 2.70 (0.82) | <0.001 |

*Source*: Lassale, Gaye, Hamer et al. (2020).

## Work status and stress

Some of the excess mortality associated with low SES may also be a consequence of the different work environments experienced by people across the socio-economic groups. This may partly reflect the physical risks associated with particular jobs. However, subtle work factors may also influence behaviour. Binge drinking, for example, has been associated with job alienation, job stress, inconsistent social controls, and a work drinking culture (e.g., Bacharach et al., 2004). Similarly, long work hours, lack of control over work and poor social support have been associated with high levels of smoking among blue-collar workers (e.g., Kouvonen et al., 2005). Other psychological research has focused on theories which suggest there is something intrinsic to different work environments that impacts directly on health – work stress.

One of the first theoretical models to systematically consider elements of the work environment that contributed to stress and illness was developed by Karasek and Theorell (1990). Their model (Figure 2.2) identified three key factors that contribute to work stress:

1. the demands of the job;
2. the degree of freedom to make decisions about how best to cope with these demands (job autonomy);
3. the degree of available social support.

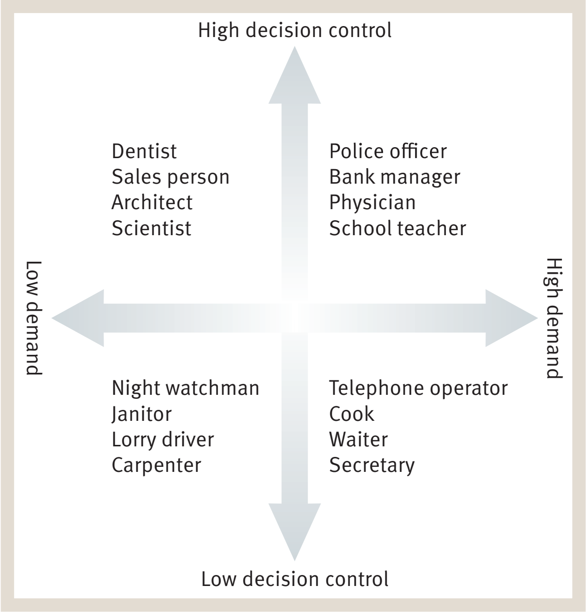

**Figure 2.2** Some of the occupations that fit into the four quadrants of the Karasek and Theorell model

*Source*: Karasek and Theorell (1990).

The theory differs markedly from previous theories that suggested occupational stress was an outcome of the demands placed on the person – the classic 'stressed executive'. Instead, it suggests that only when high levels of demands are combined with low levels of job autonomy, and perhaps low levels of social support (a situation referred to as high job strain), will the individual feel stressed and be at risk for disease. When an individual experiences high levels of demand combined with high levels of autonomy (e.g. being able to choose when and how to tackle a problem) and good social support, they will experience less stress. In contrast to the 'stressed executive' model, those in high-strain jobs are often blue-collar workers or people in relatively low-level supervisory posts.

The majority of studies exploring the health outcomes of differing combinations of these work elements support Karasek's model. Kuper and Marmot (2003), for example, found that within their cohort study of over 10,000 UK civil servants, those with low decision latitude and high demands were at the highest risk of developing coronary heart disease. Similarly, Clays et al. (2007) reported that average **ambulatory blood pressure** at work, home and while asleep was significantly higher in workers with high job strain compared with others. Consistent with this finding, Kivimäki and Kawachi's (2015) meta-analysis revealed a 10-40 per cent increased risk for CHD and stroke (as well as type 2 diabetes) among individuals with high job strain. By contrast, there is no evidence that job strain is related to the development of cancer.

An alternative model of work stress has been proposed by Siegrist et al. (1990). They suggested that work stress is the result of an imbalance between perceived efforts and rewards. High effort with high reward is seen as acceptable; high effort with low reward combine to result in emotional distress and adverse health effects. In a five-year longitudinal study tracking over ten thousand British civil servants (Stansfeld et al., 1998) both Karasek's and Siegrist's theories received some support: lack of autonomy, low levels of social support in work, and effort–reward imbalance each independently predicted poor self-report physical health. Later studies, such as Dragano et al.'s (2017) study of over 90,000 workers have also revealed modest but significant associations between effort-reward imbalance and the development of heart disease.

Even more impressively, Bosch et al. (2009) found that high levels of work stress, indicated by high workload, low social support, and high effort–reward imbalance were associated with increasingly impaired immune function, to the extent they considered work stress to 'contribute to immunological aging'. Summarising the data to date, Siegrist and Li (2017) noted that effort-reward imbalance was consistently associated with altered blood lipids, and risk of metabolic syndrome. The model was less consistently associated with high blood pressure and/or heart rate, altered immune function and inflammation, and cortisol levels.

Finally, shift work has also been associated with poor health. Summarising the data from 38 meta-analyses and 24 systematic reviews, Kecklund and Axelsson (2016) concluded that shift work was consistently associated with increased risk for accidents, and modest but significant increases in risk for type 2 diabetes, weight gain, coronary heart disease, stroke, and cancer. Importantly, this impact seems to be primarily associated with the loss of sleep associated with night and early morning shifts,

ambulatory blood pressure

blood pressure measured over a period of time using an automatic blood pressure monitor which can measure blood pressure while the individual wearing it engages in their everyday activities.

not shift work *per se*. This is likely to exert its influence through its negative impacts on immune function, and metabolic changes including those associated with obesity and heart disease (Haus and Smolensky, 2013).

Stress does not stop at work, and it does not stay at home. The stresses involved in both settings may combine to jointly impact on both mental and physical health. One form of this combined risk can be found in a phenomenon known as work–home spillover: the continuation of responsibilities within the home after work. Although there are some exceptions, this still affects more women than men (Mennino, Rubin and Brayfield, 2016), and where it occurs it can adversely impact on health. Hämmig et al. (2009), for example, found that around 12.5 per cent of their sample of Swiss employees had a high work–life spillover, and those in this category were most likely to report poor health, anxiety and depression, lack of energy and optimism, serious backache, headaches, sleep disorders and fatigue. High work stress combined with high work–home spillover can combine to be particularly deleterious (Oshio, Inoue and Tsutsumi, 2017).

Spillover effects may also influence the health of the wider family. Devine et al. (2006) found that mothers experiencing work–home spillover, especially those from lower socio-economic groups, may compromise on things like the quality of food they cook to help cope with the time challenges of their work. Shimazu, Bakker and Demerouti, (2009) found a clear association between high work–home spillover and reduced quality of intimate relationships among Japanese workers, which impacted negatively on the worker's partner's health. More positively, when work practices are adjusted to reduce the frequency of spillover these changes may reduce smoking and excess drinking, increase levels of exercise and healthy eating, and improve sleep (Moen, Fan and Kelly, 2013).

## Insecure/precarious work and unemployment

Having a stressful job impacts on health. But not having a job may also have adverse health consequences. Gallo et al. (2006), for example, found that 51–61-year-olds who involuntarily lost their jobs were at particularly high health risk, experiencing significantly higher rates of heart attacks and stroke than those still in work. Not surprisingly, the impact of unemployment is worst for those with few savings or low financial security, which may be the key determinant of whether or not individuals experience ill-health (Tøge, 2016), particularly where this is perceived as likely to last a significant time (Lam, Cheung and Wu, 2019). The threat of unemployment may also be sufficient to adversely influence health. Dragano et al. (2005) found a combination of work stress (based on the effort–reward model) and the threat of redundancy was associated with a four-fold higher prevalence of self-reported poor health than among individuals without these problems.

Increasing numbers of individuals are now working in 'precarious' jobs: the so-called 'gig economy'. Interestingly, this type of job has the potential to improve both mental and physical health (Benavides et al., 2000). However, where this pattern of work is associated with low job security or high work–home conflict it has a negative effect on mental health and a range of physical health problems (Virtanen et al., 2002; Mutambudzi et al., 2017).

### WHAT DO YOU THINK?

At a time of economic stress, jobs become more difficult to find, careers more difficult to develop. The stress associated with precarious employment, failing to find a satisfying job that leads to a desired career, or having no job at all, can affect people throughout the lifespan. How may these different stresses affect individuals early in their working life, in middle age, and when approaching retirement? And how may individuals, employers, or even the government moderate any negative experiences at each stage within the working life?

# Minority status and health

A second factor that delineates between people in society is whether or not they occupy majority or minority status within the population. These difference, may be physically obvious through skin colour or visible evidence of disability. They may be less obvious, as in the case of people from the LGBTQ+ plus community, but may spring from similar factors, including 'minority stress'; experience of, or anticipated, discrimination; higher levels of health-risk behaviours (Westwood et al., 2020);

reluctance to seek care due to fear of discrimination; and relatively high experiences of economic difficulties (Phillips et al., 2020). Of particular note is that people from some ethnic groups, including people of colour, appear to have been disproportionately affected by the COVID-19 pandemic, with a higher proportion of people from these populations both developing and dying from COVID-19 infection than white patients (e.g., Sapey et al., 2020; see also 'Research focus'). By contrast, while members of the LGBTQ+ community appear not to have been directly affected in terms of the impact of COVID-19, they may be more at risk of mental health problems as a consequence of the pandemic perhaps due to a lack of emotional support and even increased discriminating attitudes (Phillips et al., 2020).

In searching for explanations of the relatively poor health among people in minorities, a number of issues have to be borne in mind. Perhaps the most important is that a disproportionate number of them also occupy low socio-economic groups. Before suggesting that being in a minority *alone* influences health, the effects of these socio-economic factors need to be excluded. This can be done by comparing disease rates between people in minorities and people from the majority population matched for income or other markers of SES, or by statistically partialling out the effects of SES in comparisons between majority and minority populations. Once this is done, any differences in mortality between the two groups lessen markedly. In one US study of ethnic disparities in risk for CHD, for example, Karlamangla et al. (2010) concluded that the majority of excess risk among Black and Hispanic men was largely related to their socio-economic status: the impact of ethnicity while of relevance was less strong.

Socio-economic status also exerts an influence within ethnic groups. People in higher socio-economic groups generally live longer and have better health throughout their life than those with less economic resources (Karlamanga et al., 2010). However, there are some exceptions to this rule. In the US, for example, Merkin et al. (2009) found a strong SES-health gradient among Black Americans, but none among citizens of Mexican origin or Caucasians. Similarly, Tobias and Yeh (2006) found a strong relationship between SES and health among New Zealand Maoris, but no such gradient among Pacific and Asian populations. Despite these cautionary notes, there is a general consensus that ethnicity impacts on health, albeit to differing degrees, and a number of explanations for these differences have been proposed.

## Differential health behaviours

The behavioural hypothesis suggests that variations in health outcomes may be explained by differences in behaviour across social and ethnic groups. In a UK study, Bhopal et al. (2002), for example, reported that male Bangladeshi immigrants had a higher fat diet than most other ethnic groups, while Europeans were typically more physically active than people with families of origin from India, Pakistan or Bangladesh (Hayes et al., 2002). In the US, Sharma et al. (2004) found that non-Hispanic Black men were twice as likely as the other ethnic groups they sampled (Whites and Hispanics) to engage in CHD-risk behaviours. Smalley, Warren and Barefoot (2016) identified a number of what they described as 'stark' differences in health compromising behaviour across groups with differing gender identities or orientations. Groups who engaged in particularly high levels of health risk behaviours included transgender women (poor diet and exercise), cisgender men (high alcohol-related risk-taking), bisexual people (substance use), and both transgender and pansexual men (self-harm). Similarly, Loza et al. (2020) found that young adults in sexual or gender minorities were more likely to engage in health compromising behaviours including smoking, marijuana use, high alcohol consumption, and HIV risk behaviours. Despite these differences, they may only account for a proportion of the increased health risk such individuals experience. Other explanations are also relevant.

## Stress

A second explanation for the health disadvantages of people in minority groups focuses on the psychosocial impact of occupying minority status. People from minorities may experience wider sources of stress than majority populations as a consequence of specific stressors such as discrimination, harassment, and the demands of maintaining or shifting culture. So powerful is this effect, Carter et al. (2019) found that genetic changes indicating more rapid ageing were predicted by early life experiences of discrimination. In a longitudinal study of a cohort of African Americans, they found that high levels of discrimination experienced between the ages of 10–15 years were predictive of depression between the ages of 20–29 years (the final age this cohort was studied), which in turn was significantly associated with 'accelerated cellular-level aging'. Discrimination explained 32 per cent of the variance in aging at this time. This effect was independent of health behaviours, such as smoking and alcohol consumption. From a similar perspective, Todorova et al. (2010) identified depression as a pathway through which discrimination towards Puerto Ricans living in the USA led to higher levels of a number of diseases.

The link between stress, depression and disease opens the potential for wider links between discrimination and health. Noh et al. (2007), for example, identified what they termed ‘overt’ and ‘subtle’ discrimination, and found the experience of overt discrimination was associated with low positive affect, while the experience of subtle discrimination was associated with high levels of depressive symptoms, both of which may increase risk for a number of diseases. Within the LGBTQ+ community, there is a clear association between these types of individual discrimination and depression (e.g., Logie et al. 2017). Discrimination at a wider, population, level can also impact on mental health. The term ‘neighbourhood racial discrimination’ has come to mean discrimination at multiple levels including limited access to valued resources including jobs, education, and targeting by police. Above these functional issues is the higher-level perception that one’s racial group is devalued in society. These processes and beliefs have been shown consistently to predict mental health problems including depression (e.g. Russell et al., 2018) and lie at the heart of the Black Lives Matter movement (https://blacklivesmatter.com). These influences may also clearly be relevant to other communities such as LGBTQ+.

Discrimination may impact via number of biological pathways, including impaired immune function associated with chronic stress. Giurgesu et al. (2016), for example, found higher levels of systemic inflammation in pregnant African American woman than comparable controls, while Currie et al. (2020) found discrimination scores to explain 22 per cent of allostatic load scores (an index of ‘wear and tear’ and accumulated loss of effectiveness of a range of systems including the cardiac, metabolic and immune systems). In an interesting experimental study of one potential mechanism, Clark and Gochett (2006) measured blood pressure, perceived racism, and the coping responses a sample of black American adolescents used in response to racism. They found blood pressure did not vary according to the level of racism the participants reported having experienced. However, blood pressure was highest among those individuals who were both subject to racism and whose coping response was to not ‘accept it’: individuals who perhaps became angry in response to racist behaviours. Accordingly, one contributor to high blood pressure in young black people may be chronically high arousal as part of a negative emotional or behavioural response to a variety of stressors, including racism.

## Accessing healthcare

A third explanation for the relatively poor health among some ethnic groups may be found in the problems accessing healthcare. The situation in the USA was succinctly summarised in a report produced by the US Institute of Medicine (2002), which noted that:

- African-Americans and Hispanics were likely to receive lower quality of care across a range of diseases, including cancer, CHD, HIV/AIDS and diabetes;
- African-Americans were more likely than whites to receive less desirable services, such as amputation of all or part of a limb;
- disparities were found even when clinical factors, such as severity of disease, were taken into account;
- disparities were found across a range of clinical settings, including public and private hospitals, and teaching and non-teaching hospitals;
- disparities in care were associated with higher mortality among minorities.

This situation is not limited to this time period (see Becker and Granzotti, 2018), the US (e.g., Szcepura 2005), or people distinguished by their ethnic group. Ayhan et al.’s (2020) review, for example, revealed up to 42 per cent of respondents across a number of studies reported having experienced discrimination as a consequence of their gender or sexual identity. This typically took the form of discriminatory attitudes and the refusal of what was viewed as necessary medication.

Accessing preventive health can also be problematic for people in some ethnic groups; at least in part because they may choose not to access any available services. Low numbers of female family doctors in some areas of the UK, for example, have negatively impacted on Asian women’s uptake of screening, while language and lack of knowledge can be a barrier even in culturally diverse geographical areas (Thomas, Saleem and Abraham, 2005). In addition, many Muslim women do not access screening programmes as a result of a fatalistic attitude towards

### IN THE SPOTLIGHT

As noted in the main text, almost all ethnic minorities in the UK have experienced higher levels of COVID-19 and worse prognoses if infected. A number of psychosocial reasons for this increased risk have been posited by a range of authorities such as the US, Centers for Disease Control including:

- Significantly less people in a range of ethnic minorities reported a decrease in working hours (e.g., on furlough) than those in the majority population. In addition, a higher proportion of people from ethnic minorities work in essential areas of high risk of COVID-19 infection, including factories, public transport and caring roles.
- On a related issue, people in ethnic minorities may be in less stable jobs than the majority population, making it more difficult to change or leave jobs they are concerned may increase their risk of infection. They may also be less likely to take time off work if they feel ill, leading to higher severity of symptoms and disease transmission.
- People in ethnic minorities are more likely to live in crowded or poor housing, making it difficult to follow prevention strategies.
- People in ethnic minorities were more likely than the majority of the population to already have co-morbidities that placed them at increased vulnerability to COVID-19, including cardiac disease and diabetes.

developing cancer (In sha'Allah: 'if it is God's will') or the belief that developing cancer would be a sign of God's punishment, embarrassment in relation to female circumcision, as well as more practical problems such as use of language and difficulties in travel (e.g. Padela et al., 2014). Accordingly, differential use of healthcare resources by people from some ethnic groups may result from a complex interaction between the types of healthcare available to them and choices they make on whether and how to access them.

## Gender and health

We have already considered the health of people in the LGBT+ community in the context of minority status and discrimination. Here we return to the more traditional binary approach to gender, comparing the health of men and women. An average woman's life expectancy in almost all industrialised countries is significantly greater than that of men. In the UK, for example, women have an average life expectancy of around four years longer than men (81.6 years for women; 77.4 years for men: www.statistics.gov.uk). A large contributor to this difference is the earlier onset of CHD in men than in women. Nearly three-quarters of those who die of a myocardial infarction (MI) (see Chapter 8 ☛) before the age of 65 years are men. However, of the men and women who do survive to the age of 65 years, women are still likely to live the longest. Okamoto (2006), for example, found that Japanese women aged 65 years were likely to live a further 22.5 years; men were likely to live an additional 17.4 years.

As can be seen in Table 2.2, a greater proportion of men die from a range of disorders before the age of 65 than do women. Despite these differences in disease rates and mortality, though, men typically report higher levels of self-rated health and contact medical services less frequently than women, while women report higher levels of physical symptoms and long-standing illnesses than men (Lahelma et al., 1999). It is worth noting that while this pattern of mortality is common among industrialised countries, the pattern of health advantage is often different in industrialising countries. Here, differences in the life expectancy of men and women are smaller and in some cases are reversed: women are more likely to experience higher rates of premature illness and mortality than men as a result of the experience of pregnancy and its associated health risks, as well as inadequate health services.

**Table 2.2** Relative risk of men dying prematurely (before the age of 65) from various illnesses in comparison with women

| Cause | Male/female ratio |
|---|---|
| 1. Heart disease | 1.5 |
| 2. Cancer | 1.4 |
| 3. Stroke | 1.0 |
| 4. Chronic obstructive lung disease | 1.3 |
| 5. Accidents | 2.2 |
| 6. Diabetes | 1.4 |
| 7. Alzheimer's disease | 0.7 |
| 8. Influenza and pneumonia | 1.4 |
| 9. Kidney disease | 1.4 |
| 10. Septicaemia (blood infection) | 1.2 |
| All causes | 1.4 |

*Source*: UK Office for National Statistics (https://www.ons.gov.uk).

## Biological differences

Perhaps the most obvious explanation for the health differences between men and women is that they are biologically different: being born female may bring with it a natural biological advantage in terms of longevity. Women, for example, appear to have greater resistance to infections than men across the lifespan. Other biological explanations have considered the role of sex hormones. For some years, it was thought that high levels of oestrogen in pre-menopausal women delayed the onset of CHD by reducing the tendency of blood to clot and keeping blood cholesterol levels low, and this idea still holds some traction. However, data from a variety of sources, including Lawlor et al. (2002) who reported rates of CHD in women living in the UK and Japan, found no evidence of any reduction of risk prior to the menopause or increase in risk following it. In addition, replacing oestrogen following the menopause has not been found to decrease the risk for CHD (The Women's Health Initiative Steering Committee, 2004).

Our understanding of the role of testosterone in men has also changed over time. High levels of testosterone were thought to increase risk levels of **atheroma**, and increase risk for MI. Now, the reverse appears to be true, and the majority of studies (e.g. Malkin et al., 2010) suggest high levels of testosterone are considered to be *protective* against CHD, probably as a consequence of its impact on lipids within the blood: high testosterone is associated with low levels of **HDL cholesterol**.

A second apparently biological cause of higher levels of disease in men involves their greater physiological response to stress than women. Men typically have greater increases in stress hormones and blood pressure in response to stressors than women, which may place them at more risk for CHD. However, there is increasing evidence these differences may not be the result of innate biological differences between the genders. Sieverding et al. (2005) found that blood pressure reactivity of men and women did not differ during a simulated job interview but did vary according to the degree of stress they reported during the interview. Similarly, Newton et al. (2005) found no gender differences between men's and women's blood pressure and heart rate during discussions with previously unknown individuals. Dominance, and not gender, was consistently associated with blood pressure reactivity; with men who were challenged by a highly dominant male partner experiencing the greatest increase in blood pressure (and probably the most stress). It seems that it is not so much the gender of the individual that drives their physiological reactivity: rather, it is the type of stresses that the person is exposed to or the psychological response they evoke.

## Behavioural differences

Further evidence that gender differences in health and mortality are not purely biological stems from studies that show clear and consistent health-related behavioural differences between men and women. In results typical of this type of study, Kritsotakis et al. (2016) examined the prevalence of a range of health promoting/risky behaviours and how they clustered in a population of 100 young males and females. Overall, men had higher aggregate risk scores, with lower rates of health-promoting behaviours such as oral hygiene, and higher rates of a range of unhealthy behaviours including consumption of red meat and junk food, binge drinking, use of cannabis, a higher number of sexual partners, and higher BMIs. Women

atheroma

fatty deposit in the intima (inner lining) of an artery

HDL cholesterol

the so-called 'good cholesterol': see Chapter 8 ☛

were less likely to smoke, and no gender differences were found in the prevalence of protected sex, breakfast and fruit and vegetable consumption, and the frequency of having been sunburnt. In a similar study involving an even larger population, Olson, Hummer and Harris (2017) extended these analyses to calculate that 40 per cent of men in their general population sample clustered into a group characterised by unhealthy behaviour (e.g., poor diet, no exercise, substance use), compared to only 22 per cent of women.

Not only do men engage in more health-risking behaviours, they are also less likely than women to seek medical help when necessary. Men visit their doctor less frequently than do women, even after excluding visits relating to children and ‘reproductive care’. Socially disadvantaged men are even less likely to consult a doctor than their higher SES counterparts when they are ill (Wang et al., 2013). The reasons for these behavioural differences may be social in origin. Dolan’s (2011) interview-based study, for example, is one of many linking a range of masculinity beliefs that lead to low uptake of medical treatment:

> I think men have got to be tougher. They don’t want to be a sissy going to the doctor all the time . . . Hypochondria is something you would associate with a woman . . . And women well they have their troubles. They have got more complicated bits . . . In a way it’s all right for a woman to admit that she is physically failing . . . somehow it is easier in a way. But for a man to say he is having physical problems . . . it’s just not as easy.

Further showing the power of gender stereotypes, Mahalik et al. (2007) found that masculine beliefs were stronger predictors of risky health behaviours including smoking and alcohol abuse than demographic variables such as education and income. These may be established relatively early in life: adolescents with traditional masculine beliefs are less likely to attend their doctor for a physical examination than those with less traditional beliefs (Marcell et al., 2007). We noted earlier that the one health-promoting behaviour that men consistently engage in more than women is leisure exercise. This may also act as a marker of masculinity and power and carry a social message as well as having implications for health.

Unfortunately, inequalities in power between the sexes may also adversely impact on women’s health. One example of this can be found in the context of sexual behaviours, in which women are frequently less empowered than men. Blythe et al. (2006), for example, found that 41 per cent of young women aged 14–17 years in their US sample reported having unwanted sex during a three-month period. This was associated with lack of sexual control and lower use of condoms (see also Hoffman et al., 2006). Similarly, Chacham et al. (2007) found that Brazilian women aged between 15 and 24 years old who had been victims of physical violence by a partner or whose partners restricted their mobility were less likely to use condoms than those with more autonomy and control. Such behaviours clearly place them at risk of a variety of sexually transmitted diseases.

## Economic and social factors

The negative impact of adverse socio-economic factors discussed earlier in the chapter does not affect men and women equally. In the UK, for example, nearly 30 per cent of women are economically inactive, and those in work are predominantly employed in clerical, personal and retail sectors in low-paid work (Office for National Statistics 2020). About two-thirds of adults in the poorest households in the UK are women, and women make up 60 per cent of adults in households dependent on Income Support (a marker of a particularly low income) (see also discussion in World Economic Forum 2015). Social isolation is also more frequent among women than men: women are less likely to drive or to have access to a car than men, and older women are more likely than older men to be widowed and to live alone. Women also appear more vulnerable to disrupted or poor social networks than men. Irregular social contact or dissatisfaction with a social network has been associated with levels of both chronic disease (Cantarero-Prieto, Pascual-Sáez and Blázquez-Fernández, 2018) and mortality. Iwasaki et al. (2002), for example, found that in a population of older Japanese adults, women who were single and in irregular or no contact with close relatives were likely to die earlier than those with more relative contacts. In women with established diseases, including cancer, social isolation can also lead to a poorer prognosis (Kroenke et al., 2017).

## WHAT DO YOU THINK?

If health is, at least in part, a result of the social and environmental contexts in which we live, then how can society go about changing them? Most health promotion has focused on changing individual behaviours, such as smoking, lack of exercise, and so on. But is this just tinkering at the edge? Should society work towards changing the health inequalities associated with low SES? Or should we adopt the American model of 'opportunity' to become upwardly economically mobile, and those left behind fend for themselves? If society does take responsibility for reducing social inequalities, how can it set about doing so? And what about the health disadvantages of people in ethnic minorities and women with children at work? How much should society, and in particular psychologists and others involved in healthcare, involve itself in improving the health of these groups?

## SUMMARY

Poverty is the main cause of ill health throughout the world. However, psychosocial factors may also influence health where the profound effects of poverty are not found.

One broad social factor that has been found to account for significant variations in health within societies is the socio-economic status of different groups. This relationship appears to be the result of a number of factors including:

- differential levels of behaviours, such as smoking and levels of exercise;
- differing levels of stress associated with the living environment, levels of day-to-day stress, and the presence or absence of uplifts;
- differential access to healthcare and differential uptake of healthcare that is provided;
- low levels of social capital and its associated stress in some communities.

The relationship between work and health is complex. Having a job is better for one's health than not having a job. However, if the strain of having a job is combined with significant demands away from the job, this can adversely impact on health. Many women, for example, appear to have high levels of work–home spillover, with its adverse effects on both mental and physical health.

- Jobs with high levels of demand and low levels of autonomy appear to be more stressful and more related to ill-health than other types of job.
- The financial uncertainties associated with unemployment also appear to have a negative impact on health.

A third factor that may influence health is being part of a minority group as a consequence of visible or invisible differences from the majority of the population. The experience of prejudice, in particular, may contribute significantly to levels of stress and disease.

- As many people in minority groups may also occupy lower socio-economic groups, they may experience further stress as a result of this double inequity.
- Unequal access to healthcare may also impact in obvious and more subtle ways.

Gender may influence health, but not only because of biological differences between the sexes. Indeed, many apparent biological differences may result from the different psychosocial experiences of men and women. In addition:

- men engage in more health-compromising behaviours than women;
- men are less likely to seek help following the onset of illness than women;
- many women are economically inactive or in lower paid jobs than men. This makes them vulnerable to the problems associated with low socio-economic status.

## Further reading

### Websites

http://www.instituteofhealthequity.org/

Website of the University College, London Institute of Health Equity, which is aimed at 'reducing health inequalities on the social determinants of health'. An unashamedly activist site, intended to provide information to ensure improvements in health across the world. Its key publication is the 'Marmot Review', which is linked to the website.

http://www.sphsu.mrc.ac.uk/

Another resource website. The Medical Research Council's Social and Public Health Sciences Unit based at Glasgow University, with links to research on the impact on health of a range of social factors.

### Books and papers

Wilkinson, R. and Pickett, K. (2010). *The Spirit Level: Why Equality is Better for Everyone.* Harlow: Penguin.

And its follow-up:

Wilkinson, R. and Pickett, K. (2018). The Inner Level: How More Equal Societies Reduce Stress, Restore Sanity and Improve Everyone's Well-being. Harlow: Penguin.

Very accessible psycho-socio-economic arguments related to health inequalities, and its counterpart . . .

Snowdon, C.J. (2010). The Spirit Level Delusion: Fact-checking the Left's new Theory of Everything. London: Democracy Institute/Little Dice.

Dolan, A. (2011). 'You can't ask for a Dubonnet and lemonade!': working class masculinity and men's health practices. *Sociology of Health and Illness*, 33: 586–601.

An interesting qualitative study of how men's attitudes towards their masculinity can influence their health-related behaviour and health.

Hart, C.G., Saperstein, A., Magliozzi, D. et al. (2019). Gender and health: beyond binary categorical measurement. *Journal of Health and Social Behavior*, 60(1): 101–118.

The chapter has largely treated gender as a binary outcome. But of course, new models of sexuality are emerging which counter this simplistic notion of gender. This paper explores this more complex understanding of sexuality and its impact on health.

Gaffney, A. and McCormick, D. (2017). The Affordable Care Act: implications for health-care equity. *Lancet*, *389*: 1442–1452.

How much has Obama Care reduced the existing health inequalities? This critical review considers this issue.

### YouTube

https://www.youtube.com/watch?v=h-2bf205upQ

Michael Marmot, a leading researcher into health inequalities gives a talk. There are many more talks by him on YouTube. This one is longer, but really interesting if you can cope with the length: https://www.youtube.com/watch?v=UZlYnE3OhRE

https://www.youtube.com/watch?v=r0cJ7CX1ICA

The Glasgow effect – the impact of neighbourhood on health.

https://www.youtube.com/watch?v=T2mirYemCmo

Post-Obama care, the care of racial minorities is far from optimal. Nice use of implicit bias in healthcare.

Visit the website at **go.pearson.com/uk/he/resources** for additional resources to help you with your study.

# Chapter 3

# Health-risk behaviour

## Learning outcomes

By the end of this chapter, you should have an understanding of:

- how to define and describe health behaviour
- the prevalence of key health behaviours associated with elevated disease risk
- the range and complexity of influences upon the uptake and maintenance of health-risk behaviour
- some of the challenges facing health behaviour research

## The health costs of our behaviour

The World Health Organization (2019) have noted that pollution is the greatest environmental risk to health globally due to its impact on respiratory disease and some forms of cancer for example. Both large-scale industrial or agricultural practices, use of harmful chemicals and personal behaviours such as driving high emission cars, irresponsible waste disposal, or choice of aerosols can contribute to this. The next biggest risks to our health are smoking, drinking, eating and lifestyle behaviours which contribute to non-communicable diseases, such as heart disease, cancer and diabetes, which are leading causes of death. In fact, it is thought that approximately a third of deaths from such diseases could be eliminated by behaviour change. The cancer statistics, recorded across different countries, show clear associations with behavioural variations, for example, between countries with continued high smoking rates (e.g. eastern Europe), or obesity and low activity rates (e.g. UK, Spain). Behaviours often set down in childhood, adolescence or in young adulthood play a major role in mortality and morbidity, yet we rarely consider the long-term consequences of such behaviours, for example, smoking, when we start!

## Chapter outline

**Behaviour is linked to health. This has been shown over decades of painstaking research that has examined individual lifestyles and behaviour and identified relationships between these and the development of illness. For example, it has been estimated that up to three-quarters of cancer deaths are attributable to a person's behaviour. As health psychologists, one of our primary goals is to gain better understanding of the factors that predict and maintain human behaviour, in order to help develop interventions to reduce risk behaviours (this chapter) and enhance healthy behaviours (the next chapter). We provide an overview of the prevalence of key behaviours of unhealthy diet, smoking, excessive alcohol consumption or bingeing, illicit drug use and unprotected sexual intercourse, and review evidence regarding the negative health consequences of each. Both the health-risk behaviour described here and the health-enhancing behaviour described in Chapter 4 ☛ provide the impetus for many educational and public health initiatives worldwide.**

## What is health behaviour?

Kasl and Cobb (1966a: 246) defined health behaviour as 'any activity undertaken by a person believing themselves to be healthy for the purposes of preventing disease or detecting it at an asymptomatic stage'. This definition was influenced by a medical perspective in that it assumes that healthy people engage in particular behaviour, such as exercise or seeking medical attention, purely to prevent their chance of disease onset. Harris and Guten (1979), in contrast, defined health behaviour as 'behaviour performed by an individual, regardless of his/her perceived health status, with the purpose of protecting, promoting or maintaining his/her health'. According to this definition, health behaviour could include the behaviour of 'unhealthy' people. For example, an individual who has heart disease may change their diet to help to limit its progression, just as a healthy person may change their diet in order to reduce their future risk of heart disease.

These two definitions make a crucial assumption, i.e. that the behaviour is motivated by the goal of health. However many decades of behaviour research have demonstrated that people may be motivated to engage in a variety of apparently health-related behaviour, such as exercise, by reasons other than health promotion or disease prevention. For example, a person may exercise to lose weight, as a means of making social contact or simply for pleasure! Nevertheless, whether intentional or not, engaging in health behaviour may result in reduced disease risk, limit the impact or slow the progression of disease where it already exists. An elaboration of definitions of health behaviour was provided by Matarazzo (1984), who distinguished between what he termed **behavioural pathogens** and **behavioural immunogens**, which in this text we call health-risk behaviours and health-protective behaviours

**behavioural pathogen**

a behavioural practice thought to be damaging to health, e.g. smoking

**behavioural immunogen**

a behavioural practice considered to be health-protective, e.g. exercise respectively. In spite of such definitional differences, health behaviour research generally adopts the view that health behaviour is that which is associated with an individual's health status, regardless of the person's current health or motivations.

The World Health Organization (2009a) defines 'health risk' as 'a factor that raises the probability of adverse health outcomes' (p. 6). As this chapter will demonstrate, many of these risks are behavioural, although others, such as pollution or poverty, are environmental and we address these where possible (see Chapter 2 ☛). It is worth bearing in mind that perspectives on behaviour change over time – for example, thanks to medical advances we know now that smoking and excessive exposure to the sun carry significant risks for development of some cancers, whereas our ancestors did not. Skin cancer incidence has grown over the past 50 years, particularly in younger females (Ferlay et al., 2013). Our understanding of the skin cancer risk posed by sun or ultraviolet radiation (UVR) exposure, including the use of indoor tanning machines has grown. There are also however, perhaps confusingly, some health benefits to exposing our skin to the sun: for example in the early twentieth century, sun exposure was used in the treatment of skin tuberculosis, and sunlight therapy may still be offered as treatment of skin disorders. Furthermore, vitamin D, a pro-hormone which is produced in the body as a result of sunlight exposure (or through consumption of oily fish, eggs and chicken), has beneficial effects. As well as maintaining healthy teeth and bones and reducing the risk of osteoporosis by supporting the absorption of calcium, vitamin D levels in our blood (in the form of calcidiol, then converted to calcitriol by the kidneys) may protect against some cancers by being involved in regulating cell growth (Garland et al., 2009; Ware, 2017). Vitamin D from a typical diet is thought unlikely to be sufficient on its own to achieve these benefits: thus in this case a little bit of (unprotected) sunshine is beneficial (20 minutes per day).

In order to test the nature and extent of associations between behaviour and health, longitudinal (and controlled) studies are necessary. One classic example is the Alameda County study (Belloc and Breslow, 1972). This large epidemiological study collected data in 1965, 1973, 1985, 1988, 1994 and in 1999 and followed 6,928 adults (aged over 20), all of whom were healthy at the beginning of the study, for over 30 years (hence why it is still cited, as studies of this nature are rare). Analyses compared the baseline behaviours of those people who developed disease with those who remained healthy and identified key behavioural factors associated with reduced disease development and reduced mortality. These behaviours, later named the 'Alameda seven', were:

1. sleeping 7–8 hours a night;
2. not smoking;
3. consuming no more than 1–2 alcoholic drinks per day;
4. getting regular exercise;
5. not eating between meals;
6. eating breakfast;
7. being no more than 10 per cent overweight.

In the final analyses, men and women who performed six out of seven of the above behaviours lived 7 and 11 years longer respectively than those performing less than six, although in later re-analyses not snacking or not eating breakfast were not independently related to mortality. Overall, the Alameda findings contributed significantly to an evolving awareness of the associations between personal lifestyle behaviour and disease at that time. The many publications (see Housman and Dorman 2005 for a chronological review) also concluded that the benefits of performing these activities were multiplicative and cumulative: in other words, not smoking as well as being active, conferred more than twice the benefit of only performing one of these behaviours, and furthermore the longer 'immunogens' (health-protective behaviours) were engaged in, the greater the benefits to our health and longevity.

Epidemiologists consistently demonstrate that behaviour is predictive of mortality and that associations exist between specific behaviour and the onset of major illnesses such as heart disease or cancer. If, however, we are to prevent people from engaging in risk behaviour (the goal of public health and health promotion – see Chapters 6 and 7 ☛), we need to understand the psychological and social factors that contribute to the uptake and maintenance of risk behaviour or the avoidance of health-enhancing or preventive behaviour. Such studies are conducted by health and social psychologists rather than epidemiologists, and are referred to in this and the subsequent chapter, although influences are addressed more fully in Chapter 5 ☛.

## Health-risk behaviour

Extensive worldwide research into health risks in developed, developing and underdeveloped countries has shown that while specific health risks may vary across the world, there are many commonalities – such as the risk conferred by smoking tobacco. In 2018, in introducing the WHO report, World Health Statistics (WHO, 2018), the authors describe how meeting the Sustainable Development Goals aligned to health, and the reduction of premature death due to non-communicable disease in all countries irrespective of their level of development, 'will require the acceleration of progress, including action to reduce key risk factors such as tobacco use, air pollution, unhealthy diet, physical inactivity and harmful use of alcohol as well as improved disease detection and treatment' (WHO, 2018, p. 7). The report notes that while the risk of dying from non-communicable diseases, such as cardiovascular disease, chronic respiratory disease, diabetes or cancer, has decreased since 2000, an estimated 13 million people under the age of 70 still died due to these diseases in 2016. The non-communicable diseases identified above accounted for 71 per cent of all deaths (41 million of the overall 57 million deaths on 2016). These figures are staggering.

As described in Chapter 1 ☛, key risk factors are behavioural. The risk factors of alcohol use, tobacco use, high blood pressure, high body mass index, high cholesterol, high blood glucose, low fruit and vegetable intake, and physical inactivity account for over 60 per cent of cardiovascular deaths globally (includes heart disease, heart attacks). Within EU Member States cardiovascular diseases accounted for more than a quarter of all deaths in 2017 and if stroke is included as another circulatory disease, this increases to 37 per cent (EU Eurostat, 2020). Interestingly, this figure is higher in women (40 per cent of all deaths) than in men – perhaps reflecting women engaging in higher levels of risk behaviour (OECD, 2018). Cancer accounted for 23 per cent of all deaths among women in 2017 (mainly breast or lung cancer), but 29 per cent of all male deaths (mainly lung or colorectal cancers).

For reasons of length, we cannot address all risk factors in this chapter, but just to highlight one particularly horrendous and thought-provoking fact revealed in global comparisons: over 2 million childhood deaths occur *every year* in low-income countries as a result of being underweight, whereas in moderate- to high-income countries, including North America and Europe, almost 2 million people die each year as a result of an obesity-related disease. While in this text the behaviours associated with high levels of **mortality** in developed countries are discussed in more detail (as they have attracted the greatest attention from health psychologists to date), we do attempt to present a global picture where possible.

Risk factors are commonly related to the following health conditions:

- *heart disease*: smoking tobacco, high-cholesterol diet, lack of exercise;
- *cancer*: smoking tobacco, alcohol, diet, sexual behaviour;
- *stroke*: smoking tobacco, high-cholesterol diet, alcohol;
- *pneumonia, influenza*: smoking tobacco, lack of vaccination;
- *HIV/AIDS*: unsafe/unprotected sexual intercourse.

With the exception of HIV/AIDS, these diseases are more common in middle age and beyond than in younger people. Given the worldwide increase in the proportion of the population aged 65 or above, the prevalence of such diseases in our communities will make increasingly significant demands on healthcare systems. To illustrate this point further, approximately 5 per cent of the world population in 1950 were aged over 60; by 2015 this had increased to 12 per cent (900 million people) and by 2050 this is predicted to increase to 22 per cent – a massive 2 billion people in this age bracket (WHO, 2018). Within this, those over 80 years old (the 'oldest-old') is likely to increase from 11 per cent in 1940 to 20 per cent by 2050. The implications of such statistics for health and social care services are clear, as is the need for health promotion directed at the elderly (see Chapter 7 ☛). The number

**mortality**

death – generally presented as mortality statistics, i.e. the number of deaths in a given population and/or in a given year ascribed to a given condition (e.g. number of cancer deaths among women in 2000).

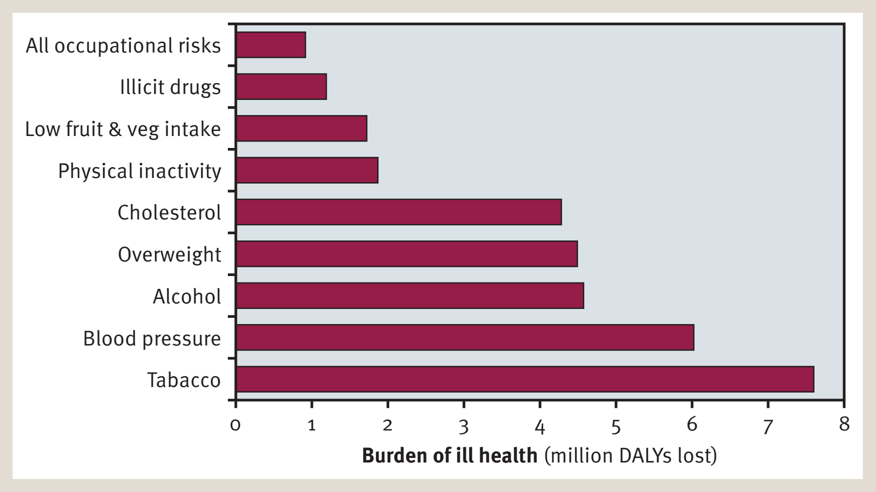

**Figure 3.1** The burden of ill health that can be attributed to behaviour or behaviour-related conditions

*Source*: Anderson and Baumberg (2006).

of healthy life years lost due to behaviour or behaviour-related conditions is significant, as shown in Figure 3.1. These EU data relate to DALYs – disability-adjusted life years – i.e. the number of years lost due to ill health or disability as well as due to early death, thus combining mortality and morbidity into one figure.

In order to gain understanding of risk behaviour, which in turn effectively informs the development and delivery of interventions (see Chapters 6 and 7 ☛) the following sections describe the prevalence, patterns and consequences of use of smoking tobacco, alcohol, and other illicit drugs before turning attention to key known psychosocial influences thereon.

Globally, as noted previously, smoking and drinking alcohol are leading risks for death and contribute to a significant disease burden, including physical **morbidity**. As with illicit drug use these legal behaviours have significant dependence potential and create significant social consequences. It is therefore unsurprising that multidisciplinary research has put them under scrutiny (epidemiological, psychological, social, economic), and that both national and global health policy provides many guidelines and recommendations.

morbidity

costs associated with illness such as disability, injury

# Smoking

## Prevalence of smoking

After caffeine and alcohol, nicotine is the next most commonly used psychoactive drug in society today. There have been some positive signs of a downturn in the prevalence and uptake of smoking over the past 50 years, and this is slowly being reflected in some of the cancer death statistics. Approximately 80 per cent of men and 40 per cent of women smoked in the UK during the 1950s, decreasing to just over 20 per cent in the English adult population aged over 16 years in 2002 (ONS, 2012; British Heart Foundation, 2012; Health and Social Care Information Centre, 2013). Jumping forward to 2016, the UK data derived from WHO figures (WHO, 2018) show an age standardised prevalence of current tobacco smoking in those aged 15 years or older of less than 20 per cent in both genders, which is much lower than in the 1950s and relatively low now compared to many other parts of Europe. Overall, the proportion of daily smokers in 2014 (EU Eurostat, 2015) ranged from 8.7 per cent in Sweden to 27.0 per cent in Greece and 27.3 per cent in Bulgaria (see Table 3.1). It is estimated that in 2020 one in four men across Europe are daily smokers, and one in six women (Eurostat, 2020).

The lower prevalence in the UK has been attributed in part to the fact that legislation came into force

**Table 3.1** Proportion of daily smokers of cigarettes (aged over 15 years), Europe 2014

| | Total | Men | Women | Gender difference (percentage points) |
|---|---|---|---|---|
| | | % | | |
| **EU-28 (1)** | 18.4 | 21.9 | 15.1 | 6.8 |
| **Belgium (2)** | 16.8 | 18.5 | 15.3 | 3.2 |
| **Bulgaria** | 27.3 | 35.4 | 19.9 | 15.5 |
| **Czech Republic** | 21.2 | 27.1 | 15.6 | 11.5 |
| **Denmark** | 12.3 | 12.6 | 11.9 | 0.7 |
| **Germany** | 15.0 | 16.4 | 13.6 | 2.8 |
| **Estonia** | 22.7 | 31.8 | 15.0 | 16.8 |
| **Ireland** | | | | |
| **Greece** | 27.0 | 33.3 | 21.3 | 12.0 |
| **Spain** | 22.2 | 26.2 | 18.5 | 7.7 |
| **France** | 20.5 | 22.9 | 18.3 | 4.6 |
| **Croatia** | 24.5 | 28.8 | 20.5 | 8.3 |
| **Italy** | 17.4 | 21.6 | 13.4 | 8.2 |
| **Cyprus** | 25.2 | 37.3 | 14.0 | 23.3 |
| **Lativa** | 24.1 | 36.0 | 14.5 | 21.5 |
| **Lithuania** | 20.2 | 33.6 | 9.2 | 24.4 |
| **Luxembourg** | 13.8 | 15.6 | 12.0 | 3.6 |
| **Hungary** | 25.8 | 31.6 | 20.7 | 10.9 |
| **Malta** | 18.9 | 21.4 | 16.5 | 4.9 |
| **Netherlands** | 17.2 | 18.9 | 15.6 | 3.3 |
| **Austria** | 23.9 | 26.0 | 22.0 | 4.0 |
| **Poland** | 21.9 | 27.8 | 16.6 | 11.2 |
| **Portugal** | 16.3 | 22.7 | 10.7 | 12.0 |
| **Romania** | 19.8 | 32.2 | 8.3 | 23.9 |
| **Slovenia** | 18.0 | 20.6 | 15.6 | 5.0 |
| **Slovakia** | 22.6 | 30.0 | 15.6 | 14.4 |
| **Finland** | 11.6 | 12.7 | 10.5 | 2.2 |
| **Sweden** | 8.7 | 7.5 | 9.8 | -2.3 |
| **United Kingdom** | 13.7 | 14.4 | 13.1 | 1.3 |
| **Norway** | 12.5 | 12.7 | 12.3 | 0.4 |
| **Turkey** | 27.2 | 41.7 | 13.1 | 28.6 |

(1) Estimates.
(2) Data with low reliability.
*Source*: Eurostat, 2015.

in 2006/2007 (Scotland 2006, rest of UK 2007) which prohibited smoking in enclosed work or public places; however, costs and other factors may also play a role (see also Chapter 5 ☛ for likely psychosocial influences). Other countries followed with similar tobacco-control policies, but some much later; for example Austria only brought in smoke-free legislation for public places in 2019. Other smoking legislature changes, such as an increased taxation, increased legal age from 16–18 years, reduced sponsorship marketing (in Formula One racing for example) or the use of plain packaging, have all been considered potential deterrents (e.g. Hiscock et al., 2019).

Although there are some minor variations in figures depending on which Survey statistics are employed (e.g. Department of Health UK data vs Health Survey for England), overall the UK figures beat the target of 21 per cent by 2010 set out in 2004 (UK Parliament, 2004). The figures are even lower in England, according to the most recent of a series of annual surveys of health and health-related behaviours of adults and children living in private households in England, the Health Survey for England 2017 (NHS Digital, 2018). This survey interviewed 7,997 adults (aged 16 and over) and 1,985 children (aged 0 to 15) and reported that 17 per cent of adults are current smokers, reflecting the aforementioned downturn.

## IN THE SPOTLIGHT

### Electronic cigarettes – electronic nicotine delivery systems (ENDS)

ENDS, or e-cigarettes, have been available since 2012 and were marketed as safe products which provide the sensation of smoking but without the known negative health consequences. However, evidence of the validity of this selling point, drawn from robust empirical studies of their chemical and toxicological properties and effects, have been challenged as time has gone on. While the science has been emerging the behaviour continued to spread, with self-reported use of e-cigarettes more than doubling among young adult Americans aged 18–25, from 19 per cent in 2010–11 to 41 per cent in the 2013 data (Ramo et al., 2015). In fact, significantly more teenagers in the USA use e-cigarettes than smoke cigarettes (US Dept of Health and Human Services, 2016), raising concerns that the social marketing is introducing e-cigarettes as a safer alternative to starting smoking.

In 2020 the World Health Organization concluded that e-cigarettes are 'harmful to your health'; even in the absence of sufficient long-term data they are concerned that there is evidence of toxic chemical compounds in the majority of ENDS (including nicotine), compounds that can cause cancer (WHO, 2020).

A review of 76 early studies (Pisinger and Døssing, 2014) had raised concerns around risks inherent in the content of the vapour, which includes volatile organic compounds such as glycerol or propylene glycol, which are carcinogenic compounds. Although these compounds are present at lower levels than in tobacco cigarettes, many users combine e-cigarettes with cigarettes and thus raise their intake levels even further. This review highlighted that many studies were methodologically flawed with significant conflicts of interest suggested in relation to those studies conducted by e-cigarette manufacturers. Particular concern has been raised for those taking up e-cigarette use in adolescence and thus facing prolonged exposure (e.g. Rubinstein, Delucchi, Benowitz and Ramo, 2018). In 2020 WHO called for ENDS to be 'kept away from children'. They pointed to a growing body of evidence that never-smoker adolescents, who start to use ENDS, double the likelihood of later taking up smoking. This has been contradicted in an American study conducted at the population level where increased vaping was seen to coincide with a reduction in the number of adolescent smokers (Levy et al., 2021). There is an obvious need to continue monitoring the relationship between adolescent smoking and ENDS uptake.

At the other end of the spectrum are those established smokers who often use e-cigarettes as an aid to quitting. Evidence as to whether these devices succeed in the long term or are better than alternative methods, such as nicotine patches or gum, is mixed. An early meta-analysis suggested not (Grana et al., 2014); however a more recent randomised trial of 886 adults attending a UK NHS Stop Smoking service, and allocated either to NRT or to e-cigarettes, with behavioural support provided also for four weeks, found that those in the e-cigarette group were almost twice as likely to still be abstinent at 12 months (18 per cent) than those on NRT (9.9 per cent) (Hajek et al., 2019). While more e-cigarette smokers than nicotine-replacement users reported throat or mouth irritation, more reported reductions in coughing and phlegm production, and only the NRT group reported feelings of nausea. Conclusions of this study were that, at least when accompanied by initial behavioural support, e-cigarettes were more effective at achieving maintained abstinence than nicotine replacement therapy.

It may be some time before we have amassed sufficiently robust and generalisable evidence as to e-cigarettes efficacy in achieving and maintaining smoking cessation, and even longer before we can truly understand any health risks. While these are likely to be significantly less than that of conventional tobacco smoking, the use of e-cigarettes particularly in those who were not previously smokers, needs urgent further study, as does the issue of whether e-cigarettes themselves act as a 'gateway' to conventional smoking behaviour.

In terms of children aged 8 to 15 years having ever smoked a cigarette, this also reduced significantly from 19 per cent in 1997, to 5 per cent in 2017 (11 per cent in those aged 13–15 years), which is very encouraging. Finally, due to the addition of new questions in 2013, 6 per cent were identified as e-cigarette smokers. Some concerns have been raised regarding the burgeoning use of e-cigarettes among the under-25s (European Commission, 2017), with as yet unclear evidence regarding long-term consequences (see 'In the spotlight').

Ethnic differences in smoking prevalence have also been reported and overall ethnic minority group figures suggest a lower prevalence than among the total population (ONS, 2021). In England, data from the 2019 Annual Population Survey reported an all-adult prevalence of smoking of 13.9 per cent, with 14.4 per cent among those of White ethnicity, compared to 9.7 per cent among those of either Black ethnicity, 8.3 per cent Asian ethnicity and 6.7 per cent Chinese ethnicity, with rates consistently higher among ethnic minority men than women. Within British South-East Asian groups Bangladeshi men have been found to be at greater risk of coronary heart disease than other groups, and this has been attributed in part to their tendency to exercise less and smoke more than their White counterparts. In contrast, the percentage of Bangladeshi, Indian and Pakistani women smoking is significantly below the general population norm (BHF, 2012).

As well as culture, there are age differences in smoking prevalence. Across Europe, prevalence was highest in men aged 25 to 34, and 35 to 44 and among women aged 45 to 54, followed by aged 20 to 24, with lowest levels seen in those over 65 (about 12 per cent of men, 8 per cent of women) (EU Eurostat, 2015). Among the more elderly, smoking was generally initiated before the medical evidence as to the health-damaging effects of smoking was clear and publicly available. Smoking in the elderly increases morbidity, disability and death (Bratzler et al., 2002), thus health promotion efforts still need to target smoking cessation in older people so as to enhance their quality of life and possibly extend their lifespan. The health gains of smoking cessation have been well documented. Although elderly groups present particular challenges to health educators, due to the consistent finding that they attribute many health consequences of smoking to general ageing processes, and that they are often highly dependent on the behaviour (psychologically and physically), interventions that combine age-relevant risk information and support are likely to be as effective in achieving smoking cessation as similar interventions in younger populations.

Although smoking prevalence has stabilised or declined in some countries, smoking remains the largest, avoidable, health risk in Europe and beyond. For example, in the USA it has been estimated that smokers on average die 10 years earlier than non-smokers (Jha et al., 2013). In Europe this is estimated at 14 years earlier on average (European Commission, 2020).

## Negative health effects of smoking

Internationally, smoking tobacco is one of the chief causes of cancer – in the lungs, larynx, throat, mouth, oesophagus, kidney, liver, bladder, stomach, pancreas, colon, rectum and cervix (National Cancer Institute, 2016). Worldwide, direct use of tobacco kills around 7 million smokers a year (compared to approximately 3 million deaths worldwide in the late 1980s), with another 1.2 million deaths among non-smokers attributed to second-hand, indirect tobacco exposure (WHO, 2021). It is predicted that over 1 billion people this century will die from tobacco-related causes (WHO, 2021).

Although 80 per cent of these deaths occur in low- to middle-income countries, there is no reason for complacency in developed countries, such as the UK and most of Europe. In the UK, smoking is considered to be responsible for a fifth of all deaths, and around a quarter of cancer-related deaths (Cancer Research UK, 2021c). While smoking behaviour receives a vast amount of negative publicity arising from the death toll attached to it, nicotine is a legal drug with sale of nicotine-based substances (cigarettes, e-cigarettes, cigars) providing many tobacco companies and governments with a vast income as a result of tobacco tax.

Tobacco products contain **carcinogenic** tars and carbon monoxide, which are thought to be responsible for approximately 30 per cent of cases of coronary heart disease, 70 per cent of lung cancer and 80 per cent

carcinogenic/ carcinogenesis

substances implicated in the development of cancer cells/ the process by which normal cells become cancer cells (i.e. carcinoma)

**Photo 3.1** Do health warnings make a difference?

*Source*: Roger Utting/Shutterstock.

of cases of **chronic obstructive airways disease** among smokers. Knowledge and awareness of this varies however – for example, the 2015 Global Adult Tobacco Survey (GATS) (WHO, 2019b) conducted in China revealed that only 26.6 per cent of Chinese adults believed that smoking caused lung cancer, heart disease and stroke.

For smokers, direct intake of carbon monoxide reduces circulating oxygen in the blood, which effectively reduces the amount of oxygen feeding the heart muscles; nicotine makes the heart work harder by increasing blood pressure and heart rate; and together these substances cause narrowing of the arteries and increase the likelihood of thrombosis (clot formation). Tars impair the respiratory system by congesting the lungs, and this is a major contributor to the highly prevalent **chronic obstructive pulmonary disease** (COPD: e.g. emphysema) (see also Chapter 8 ☛). Overall, the evidence as to the negative health effects of smoking tobacco is indisputable. Those exposed to second-hand smoke are also at risk with robust evidence as to the negative effects of passive smoking. Clear associations have been shown between occupational exposure to smoke and significantly increased risk of serious respiratory and cardiovascular disease In addition passive smoking is considered to account for 25 per cent of lung cancer deaths among non-smokers. Passive smoking also carries risks to unborn babies; although many women will give up smoking during pregnancy, many do not, and has been associated with sudden infant death syndrome (WHO, 2019).

## Prevalence of alcohol consumption

Alcohol (ethanol) is the second most widely used psychoactive substance in the world (after caffeine) and in Westernised cultures at least the social use of alcohol is considered an integral part of many life events, such as weddings, birthdays and even funerals. That said, 57 per cent of a global population aged 15 years or older had NOT had a drink of alcohol in the preceding 12 months (World Health Organization, 2018).

### Recommended levels of drinking

Different individuals respond differently to the same amount of alcohol intake, depending on factors such as body weight, food intake and metabolism, the social context in which the drinking occurs, and the individual's cognitions and expectations. It is therefore difficult to determine 'safe' levels of drinking alcohol.

There is some confusion internationally as to what constitutes a 'standard' measure or 'unit' of alcohol. Many countries have specific national guidelines regarding the 'standard unit' of alcohol (Table 3.2), and guidelines regarding maximum 'gram per day'. The 'unit' size (grams of alcohol) vary as do the recommended weekly limits for males and females. Typically, European countries follow the World Health Organization quantification of one unit of alcohol equating to 10 grams of pure alcohol. This roughly

chronic obstructive pulmonary (airways) disease

a persistent airway obstruction associated with combinations of chronic bronchitis, small airways disease, asthma and emphysema

**Table 3.2** International 'Standard Unit' and daily limits* where specified (selected countries only, based on 2018 data)

| Country(ies) | Unit of alcohol (g) | Daily limits |
|---|---|---|
| Austria | 8 | Men 24g–32g, women 16g–24g |
| France | 10 | No more than 20g per day for either sex |
| Greece, New Zealand | 10 | Men no more than 30g, women no more than 20g |
| Lithuania | 10 | No more than 20g per day for either sex |
| Japan*, Singapore, Slovenia | 10 | Men no more than 20g, women no more than 10g |
| India, Latvia | 10 | Men no more than 30-40g, women no more than 20-30g |
| Finland, Sweden | 12 | Men no more than 20g, women no more than 10g (less than one unit?) |
| Germany | 12 | Men no more than 24g, women no more than 12g |
| Italy* | 12 | Men no more than 24-36g, women no more than 12-24g |
| Canada | 13.6 | Men no more than 41g, women no more than 27g |
| USA | 14 | Men 28–42g, women 14g–28g |
| Japan | 19.75 | Men 19.75g–39.5g; women no guidance |
| Some countries, such as the UK, Malta, Norway and Irelands do not provide daily guidelines | Some countries, such as the UK, Malta, Norway and Irelands do not provide daily guidelines | Japan also specifies 10g a day if over 65 years |

*Source*: AIM (Alcohol in Moderation), Sensible Drinking Guidelines, 2018; Japan's Ministry of Health, Labor and Welfare, National Health Promotion Campaign in the 21st Century (Health Japan 21); Higher Institute of Health, Italy the Epidemiology for public health, The ISTISAN 21/7 report.

approximates to half a pint of normal-strength lager or a standard single measure of spirit (1/6 gill) or wine of average strength (11–12 per cent alcohol) = 1 unit. However a standard drinking unit in Japan is defined by government guidelines as 19.75g alcohol, whereas in Europe a 'standard' drink would typically contain between 8 and 14g of pure ethanol (14g in the USA equates typically to one unit). Such differences make comparisons between countries and the data provided in research publications quite challenging, and particularly when discussing what constitutes 'binge drinking (see below), as recognised in a recent review (Kuntsche et al., 2017).

For children, the guidance recommends that remaining alcohol free until 15+ is the healthiest option (Donaldson, 2009), given evidence of longer-term consequences as described below. While the recommended guidelines on 'safe' levels of alcohol consumption for adults vary from country to country, the UK government's current recommended limit for weekly consumption is 28 units for males, and 21 units of alcohol for females. The European Commission refer to safe levels as being under 40g of alcohol a day for men (about four standard drinks, equating to the 28 units per week) and under 20g per day for women (about 2 standard drinks, thus lower than the UK's 21 units). More recently, the UK Chief Medical Officer has in fact advised both males and females not to drink over 14 units of alcohol a week in order to avoid detrimental health consequences (Drinkaware, 2019). Some guidelines also recommend one or two alcohol-free days per week. It appears from national surveys that approximately a third of men and a quarter of women exceed national drinking guidelines.

Countries who do not have national guidelines (e.g. Belgium, China, Hungary and Russia) tend to follow WHO guidelines for sensible drinking:

- Women should not drink more than two drinks a day on average.
- For men, not more than three drinks a day on average.
- Try not to exceed four drinks on any one occasion.
- Don't drink alcohol in some situations, such as when driving, if pregnant or in certain work situations and
- Abstain from drinking at least once a week.

The WHO is currently developing an action plan (2022–2030) to effectively implement a global strategy to reduce the harmful use of alcohol as a public health priority.

## Who drinks?

Globally over 40 per cent of the population are current drinkers, with this increasing to over 50 per cent in the Americas, Europe and Western Pacific. More than 26 per cent of 15–19-year-olds are current drinkers (this is 155 million adolescents) (World Health Organization,

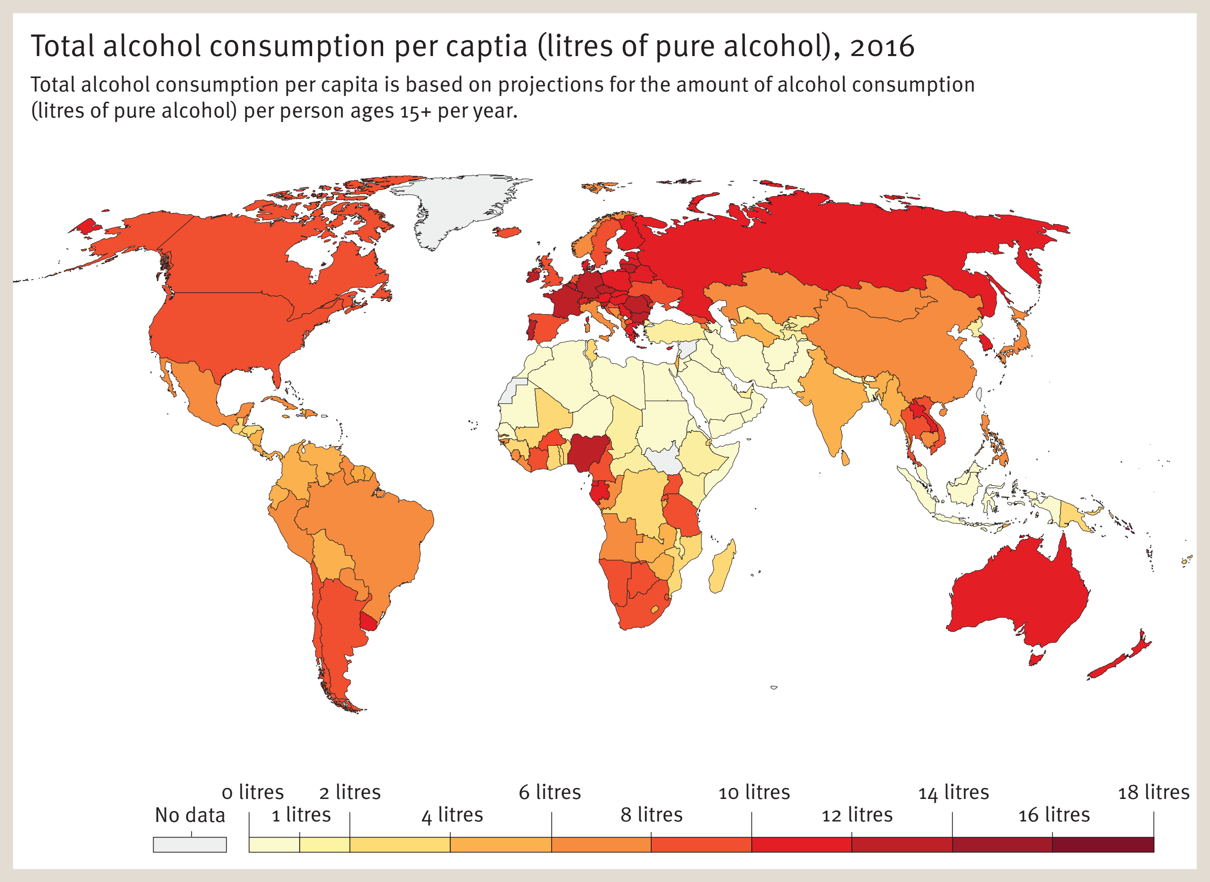

**Figure 3.2** A world map view of alcohol consumption

*Source*: Alcohol Consumption,World Bank Reterived from https://ourworldindata.org/alcohol-consumption.

2018). However there are national variations as depicted in Figure 3.2. Drinking in North Africa and the Middle East is limited (prevalence of around 5–10 per cent), compared to the highest rates seen in Eastern Europe including, Russia, Belarus, the Czech Republic and Lithuania. Western Europe need not be complacent however with a high prevalence of drinking (for example, in France 95 per cent of adults have drunk alcohol in the preceding year) and a high average level of consumption.

Worldwide, 44.8 per cent of total recorded alcohol is consumed in the form of spirits, followed by beer (34.3 per cent) and then wine (11.7 per cent) (WHO, 2018), with nationality, age and gender effects on these drink choices – Europeans for example drink more beer and wine than spirits.

In older age groups consumption over the past two decades has been relatively stable across Western Europe, although slow declines have been seen in countries where previously levels had been higher than average – including France, Spain (OECD, 2014). While the lowest prevalence of *heavy* drinking is among those over 65 years old, consumption trends do vary over time with a doubling of those exceeding UK recommended daily limits between 1994 and 2012 (see below) among both those aged 65–74 and those aged 75 years or more, with this particularly seen in women (Health and Social Care Information Centre, 2013). The resulting prevalence of around 15 per cent is a public health concern, given physiological changes in older people, the likely presence of comorbidities and potential interactions with other medicines (Knott et al., 2015).

At the other end of the age spectrum, in a comparison of 35 European countries, children in the UK showed the highest rates of alcohol consumption and binge drinking (Hibell et al., 2012). However, data from the National Centre for Social Research and the National Foundation for Educational Research (NFER) survey of over 7,000 school children aged 11–15 in 2012 (Health and Social Care Information Centre, 2013) confirmed a downward shift compared to the previous decade. There does, however, remain concern about adolescent drinking in many European countries due to its association with other behaviours (see also 'Issues')

Also, encouragingly, a decrease has been recorded in the prevalence of heavy drinking among those aged 16 to 24 years old. In fact, the 2017 Opinions and Lifestyle Survey (ONS, 2017) of a representative sample of over 7,000 adults aged 16 years or older in Great Britain reported that those in the 16–24-year-old age bracket were less likely to drink alcohol than other age groups, although when they did drink, their heaviest day of drinking exceeds the volume of alcohol consumed by the other ages (see Binge drinking below). Also, high earners and those in professional or managerial positions were most likely to have drunk alcohol in the past week.

## Binge drinking

Binge drinking, or 'heavy episodic drinking', is increasingly recognised as problematic. Binge drinking is defined as either males consuming eight or more units of alcohol on their heaviest day of drinking (equivalent to about four pints of standard strength beer or three-quarters a bottle of wine) of females consuming six or more units of alcohol on their heaviest day of drinking (equivalent to three pints of standard strength beer or half a bottle wine) (Office of National Statistics, 2018). Bingeing is more prevalent in some populations and in some sectors of the populations than others (see for example, Figure 3.3 for age and binge drinking prevalence in the UK).

Young adults typically binge more than other age groups. One example of this comes from a survey of 2,215 British university students (65 per cent female), (NUS, 2018). While 24 per cent of this sample reported

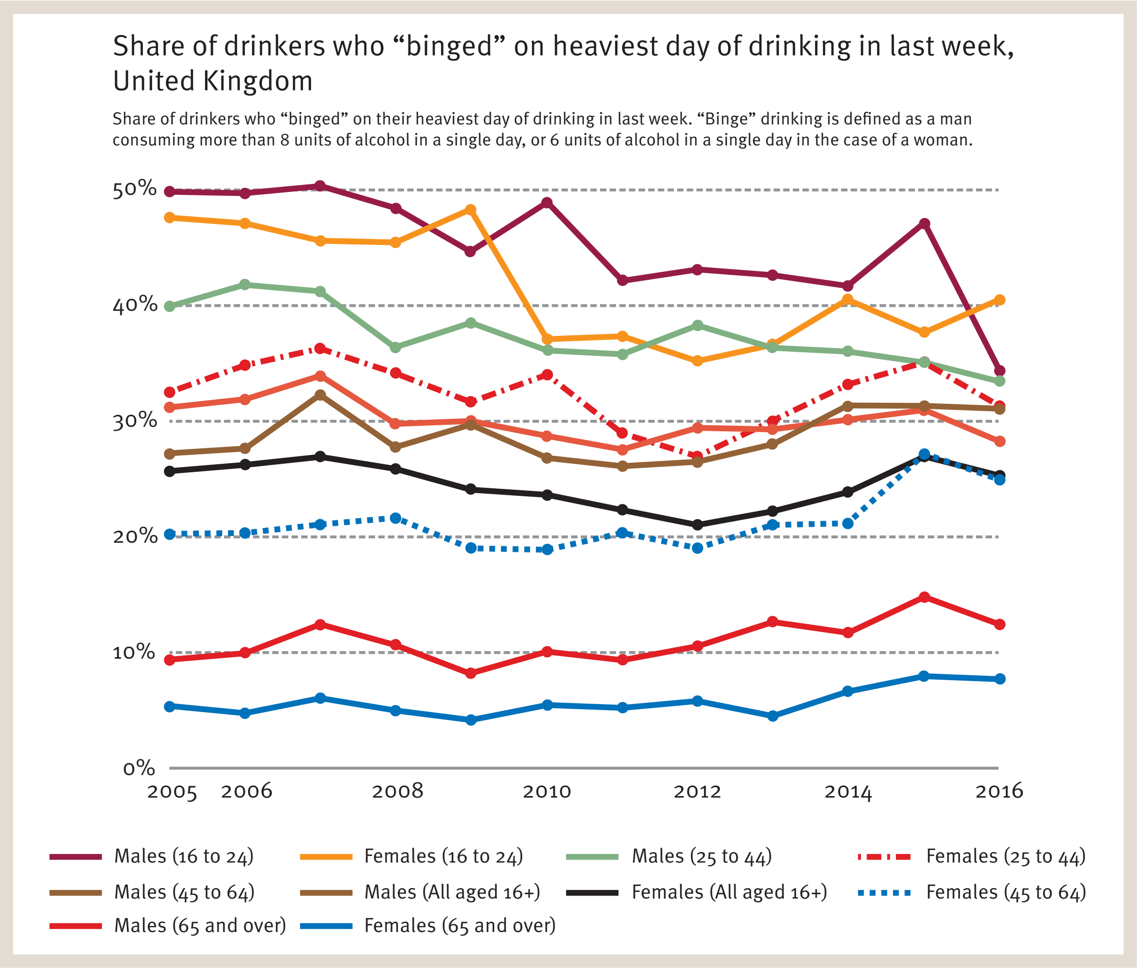

**Figure 3.3** Age and binge drinking prevalence in the UK

*Source*: Our World in Data https://ourworldindata.org/grapher/share-of-drinkers-who-binged, Office for National Statistics, 2017.

not having had an alcoholic drink in the preceding week and 27 per cent reported only one occasion of drinking, 37 per cent reported drinking at least two to three times in that week, and the remaining 10 per cent had drunk on four or more occasions. A quarter of respondents reported drinking alcohol with the deliberate intention of getting drunk at least once per week with a further 6 per cent reporting purposefully drinking to get drunk more than once per week. Although the overall average number of units consumed in the previous week was relatively low (10 units), binge drinking means that for some, all of these units are consumed on one occasion. It is notable that students and young adults may be drinking less than previous generations (e.g. see review by Davoren, Demant, Shiely, and Perry, 2016), and attitudes and norms of drinking may be changing (for example, three in four of the NUS Survey participants reported that they don't like socialising with people who get very drunk). However, there is still cause for concern with regards to hazardous binge drinking in a significant minority (Viner and Taylor, 2006; NUS, 2018).

UK adult data is presented in Figure 3.3, where it can be seen that typically around a quarter to a third of those aged 25 to 44 also engage in binge drinking, with females in this age group consistently doing this more than males, whereas in all other age groups males report binge drinking more than age-equivalent females.

While the under-25s do tend to 'binge' drink more than older individuals, data presented in Figure 3.3 highlight that significant proportions of those in older age groups also binge, thus the social (often antisocial) problems caused by binge drinking are by no means confined to those under 25 years. Those aged 25-44 years for example are likely to have jobs, more likely to have their own family and other responsibilities with which binge drinking, or regular drinking may interfere.

Drinking alcohol is still 'normalised' in student culture. In an NUS survey (2019) where the vast majority of respondents agreed to some extent that drinking and getting drunk is part of university culture (79 per cent, n = 1358). However it is notable that they did not all follow this expectation with their behaviour and only 22 per cent felt pressure from their own university friends to drink regularly and get drunk. It may be that more positive attitudes to healthy behaviours, as opposed to attitudes supportive of excessive drinking, are becoming more widespread. Furthermore, drinking excessively in one context (such as while at college or university) does not inevitably mean that one 'progresses' to alcohol dependence or indeed to the use of other substances.

In addition it should not be assumed that heavy episodic drinking or other problem drinking is more common in those less well educated or of lower socio-economic status, as evidence in this regard is quite mixed. The better educated have often been shown more likely to engage in various forms of risky behaviour but to be less likely to develop problem drinking (e.g. Caldwell et al., 2008). However, an impressive study of almost 10,000 individuals aged 34 years at the time of the study (all drawn from the British Cohort Study, which is a sample of all those born in a specific week in 1970) found that higher educational attainment *was* associated with increased odds of daily alcohol consumption and also with problem drinking, particularly among females (Huerta and Borgonovi, 2010). This is of course a very specific cohort of those in their mid-30s and so we cannot infer that relationships do not also exist at other ages, or for other forms of drinking, such as binge drinking.

Relatedly, a relationship between a person's socioeconomic status and both drinking heavily and drinking more than recommended guidelines has been reported reasonably consistently. Males and females in the 'managerial or professional' classification engage in these behaviours more than those in either 'intermediate' or 'routine and manual' professions (see also Chapter 2 ☛). Access to alcohol by means of disposable income is an important consideration.

## Negative health effects of drinking alcohol

Alcohol is commonly perceived as a stimulant; it is in fact a central nervous system depressant. Its negative effects can be considered in three ways: in terms of physiological or physical damage; in terms of immediate impact on individual behaviour; and in terms of developing dependence and longer term mental health problems. It is generally accepted that there is a linear relationship between the amount of alcohol consumed over time and the accumulation of alcohol-related physical damage and illness, including diseases such as liver cirrhosis, liver, larynx and oesophageal cancer, stroke and epilepsy. Alcohol use, at a level of around 3 to 3.5 standard drinks a day, accounts for 4 per cent of cancer incidence, specifically head and neck cancers (e.g throat, oesophagus, mouth, larynx), colorectal, breast and liver cancers) (National Cancer Institute, 2016). In terms of behavioural impact, even low doses cause behavioural disinhibition, while high levels of intoxication lead to a 25-fold increase in the likelihood of an accident, and extremely high doses severely affect respiratory rate, which can cause coma and even death. Patterns of heavy drinking laid down in late childhood and early adulthood tend to set the pattern for heavy drinking in adulthood, and alcohol-related health problems including alcohol dependence (and diseases such as liver cirrhosis) tend to accumulate in middle age.

The World Health Organization in fact notes alcohol as a causal factor in over 200 diseases (WHO, 2018). Males remain twice as likely to die from alcohol-related causes generally defined than are females, although an increase among women over the past decade has caused some concern in the UK (ONS, 2017). Within this recent UK data set death rates were highest among 55–59-year-old women and 60–64-year-old men.

There is significant variation across Europe and elsewhere in terms of alcohol-related deaths, drinking behaviours, and in the volumes of alcohol consumed (as seen also in Figure 3.3 above). Sadly for those of us living in Europe, we have the highest proportion in the world of total ill health and premature death due to alcohol (WHO Europe, 2017). Eastern European statistics however confer a *seven*-fold higher risk of dying from an alcohol-related cause than those from Mediterranean Europe (WHO Europe, 2017).

Teenage substance use has the potential to create other long-term problems for the individual including substance use escalation and associated problem behaviours (Collado et al., 2014). Although drinking is primarily a social behaviour, with many not experiencing major problems as a consequence, among young people, heavy or regular drinking has been associated with subsequent neurocognitive challenges, physical or mental health problems, behaviour problems and impaired school performance (Windle et al,, 2008; Spear, 2018). Excess alcohol consumption has also been associated with relationship breakdowns, unplanned and/or unprotected sexual activity, with alcohol found to have impaired judgements regarding (early) sexual activity and unprotected sexual intercourse (Wellings et al., 2001; Conner et al., 2008). Unplanned or unprotected sexual activity can obviously result in teenage pregnancy or sexually transmitted disease, including HIV infection (Williams et al,, 2016). Being ‘drunk’ is a commonly cited reason for first having sex when a teenager (e.g. Wellings et al., 2001). Changing adolescent risk behaviour is often challenging, given the complexity of influences thereon, as we describe in the subsequent section. There is, however, some evidence that interventions which address self-esteem issues before addressing ‘behaviour’ problems, including under-age sex, smoking and drinking alcohol, meet with greater success than those which do not (e.g. Health Development Agency Magazine, 2005) (see also Chapters 6 and 7 ☛).

**Photo 3.2** The increase in teenage binge drinking is of concern, particularly among females

*Source*: John Powell Photographer/Alamy Images.

Among older people, problem drinking has been shown to be increasing (Rao and Roche, 2017) and to be influenced by physical health, access to social opportunities and financial status, with the affluent elderly having higher rates of drinking problems than those less well off (see the systematic review by Kelly et al., 2018; Health and Social Care Information Centre, 2013). Kelly's review also found that for some individuals, however, an increase in alcohol consumption could be attributed in part to loneliness, often following bereavement.

## Are there benefits to moderate drinking?

There is evidence that moderate alcohol consumption may be health-protective. A J-shaped relationship has been found between alcohol consumption and CHD risk, i.e. abstinence confers a higher risk than moderate drinking, although not as high as the risk conferred by heavy drinking (BHF, 2012), This surprising finding has emerged from both cross-sectional and prospective studies. In terms of proposed mechanisms of action it appears that light to moderate alcohol intake reduces circulating low-density lipoprotein (LDL, 'bad fat') levels (high levels are a known risk factor for CHD). More specifically, moderate intake of red wine has been associated with reduced cardiovascular deaths, due to it being derived from red grapes which contain many different polyphenolic compounds including flavonol. Dietary flavonoids (derived mainly from apples, berries and tomatoes but also from tea and dark chocolate) are thought to effect the vascular system, reducing blood pressure and as a result offering some protection against CHD (Wang et al., 2014) and stroke (Rees, Dodd and Spencer, 2018). Rees describes the evidence with regards to peripheral vascular health (blood pressure and flow) an indicator of heart disease, as reasonably consistent, and the evidence for blood flow within the brain and thus relevant to the occurrence of stroke or other conditions such as vascular dementia, is as at an earlier stage. They note that the evidence is very mixed, drawn from studies of varying quality, many of which were not controlled studies, thus their review of randomised controlled studies offers a more cautionary summary.

It has also been suggested, drawing from evidence from laboratory or animal studies (e.g. Briviba et al., 2002) that red wine polyphenols may be beneficial to cancer risk by inhibiting the initiation of **carcinogenesis** due to their antioxidative or anti-inflammatory properties, or by slowing progression in those with cancer by inhibiting the growth of mutated cells or by inducing apoptosis, i.e. cell death. However as noted above in relation to CHD, many studies exploring the benefits of polyphenol ingestion to cancer risk have also been uncontrolled and cross-sectional. There is a need for further research with human populations and tight controls over other contributory factors. It will be some years before the evidence as to the effects of red wine drinking on people already with cancer becomes clear. In relation to coronary heart disease however, the evidence is of longer standing, and concluding that low to moderate ingestion of alcohol, and not solely red wine, has health-protective effects, is not considered unfounded (O'Keefe et al., 2018).

If the amounts of alcohol consumed are low to moderate and the pattern of drinking does not include binges, the World Health Report states that alcohol's relationship to CHD, stroke and diabetes mellitus, can be a beneficial one (WHO, 2002a), possibly even reducing mortality (Klatsky, 2008). There is some evidence also that moderate drinking among females may be more protective of CHD than among males (WHO, 2002a).

Caution is however advised before concluding from these reports, It is safer to conclude only that heavy drinking has negative effects on health that increase in line with consumption; that moderate levels of drinking may not increase risk and may in fact be protective against CHD (although any protective effects are lost on people who smoke); and that the effects of not drinking at all need further exploration, with some studies reporting that the risk of CHD was higher than average among non-drinkers. However, poorly controlled studies make it impossible to establish whether not drinking conferred the increased risk of heart disease or whether another explanation exists i.e. non-drinkers may choose not to consume alcohol because they are already in poor health, or because they are members of particular religious or ethnic groups that forbid such use but which may hide some other 'cause' of CHD.

The key term in experiencing any benefits from drinking is 'light to moderate ingestion of alcohol' (<= 1 drink per day women; <= 1–2 drinks per day men). It remains unlikely that individuals presenting to their GPs with health concerns around a family history of heart disease would be advised to increase a light alcohol consumption to a moderate one however in case heavy drinking resulted which does carry elevated risks to health! They will probably be advised to follow a low-fat diet, yet the suggested protection offered is similar.

### WHAT DO YOU THINK?

Alcoholic drinks should come with written health warnings similar to those that appear on tobacco products, with transparency about contents, the number of alcohol units per serving, drinking limit guidance, and critically information about health risks, according to the All-Party Parliamentary Group on Alcohol Harm (Alcoholchange.org, 2019).

Would evidence-based labelling with messages regarding potential health risks of drinking encourage responsible drinking behaviour among your peers? If not, why not? Are such approaches to changing health behaviour effective? Think of the patterns of smoking since graphic images appeared on cigarette packaging in the UK in 2011. Think about your own behaviour and that of others around you before you go on to read Chapters 5–7 ☛.

## Prevalence of illicit drug use

Across the European Union in 2017 it was estimated that about a quarter of adults (aged 15–64 years old) try an illicit drug in their lifetime – mainly cannabis, but for some this included amphetamines, cocaine, ecstacy and others (EMCDDA, 2018). Within a slightly narrower age range 29 per cent of England and Wales residents aged 16–59 years old in 2015/2016 had taken cannabis at least once in their lifetime, which exceeded the EU average of 25 per cent, and almost 10 per cent had taken cocaine in their lifetime.

However, unlike what is seen with alcohol, very few go on to use such substances regularly. Between 3.5 and 9 per cent of the world's population will have used an illicit drug in the past year (for example, 8.5 per cent of adults in England and Wales in 2017, (NHS Digital, National Statistics 2018)), with regular drug use tending to relate to cannabis. Even cannabis has a relatively low prevalence in terms of use 'in the past year' (7.6 per cent globally for adults). However regional variations and population differences exist; for example, across European adults aged 15–34 years, the use of cannabis in the past year increased to 14 per cent, with a figure exceeding 20 per cent seen in France and Italy. In contrast the use of cocaine, the most popular stimulant, remains around 2 per cent (with a higher 3 per cent seen in the UK, Netherlands, Denmark and Spain) (OECD, 2018). About one-quarter of a per cent will have injected across the global population.

Among younger populations, the use of Class A drugs (see Table 3.3) tends to relate to cannabis use, with a continuing downturn in prevalence reported over the past two decades. For example, while almost one in five adults aged 16–24 years in England and Wales had taken any illicit drug in 2017; this is a significant 5 per cent lower than the figures a decade previously. In addition this figure drops to around 8 per cent when Class A drugs are concerned. However the prevalence of '*ever taking*' any drug among schoolchildren aged 11–15 years old in England (Smoking, Drinking and Drug use among Young People in England, 2016; NHS Digital, 2017) showed a surprising and significant recent increase to 24 per cent, from 15 per cent reported in 2014. This was attributed to the inclusion of 'new psychoactive substances (NPAs)' and 'nitrous oxide' in the questions asked; however this is likely to only be a partial explanation. Subsequent years' data needs to be awaited to see whether this is a real trend or not.

In terms of use *in the past year*, an estimated 18 per cent of English schoolchildren reported this in 2016 and excluding the aforementioned NPAs and nitrous oxide this drops to 15 per cent – still a 5 per cent increase from the equivalent 2014 survey. In those aged 15 years the figure is around 30 per cent, for those aged 11 or 12 years this figure falls to 10 per cent or less. Almost half (49 per cent) of these school children report getting the substances from a friend, generally one of the same age. Worryingly over a quarter (26 per cent) report obtaining the substance they used from a dealer.

### Negative health effects of substance/illicit drug use

Dependent or problematic use classed as a drug abuse disorder tends to correspond to opiate use. Approximately 40 deaths per million of the population aged between 15 and 64 were attributed to illicit drug use in 2012 (United Nations, 2014) and illicit drug use and its associated consequences remain a major cause of young adults in Europe – both through direct consequences of use such as overdose, and indirectly through the associated accidents, violence, and suicides and from drug- and behaviour-related diseases such as Hepatitis C and HIV.

**Table 3.3** Classification of drugs, UK

| Drug | Mode of use | Classification |
|---|---|---|
| Amphetamines | Inject | A |
| Ecstacy | Oral | A |
| Cocaine | Sniff, inject | A |
| Crack | Inject, smoke | A |
| Heroin | Smoke, inject, sniff | A |
| LSD | Oral | A |
| Magic Mushrooms | Oral | A |
| Methadone | Oral | A |
| Amphetamines | Sniff, oral | B |
| Barbiturates | Oral, inject | B |
| Cannabis* | Smoke, oral | B |
| Synthetic cannabinoids (e.g. Spice) | Smoke, oral | B |
| Ritalin | Oral | B |
| Codeine | Oral, inject | B |
| Minor tranquillisers | Oral, inject | B/C, depends on drug |
| Mephedrone | Oral, inject | B |
| Ketamine | Oral, sniff, inject | B |
| GHB (Gamma-Hydroxybutyrate) | Oral, inject | C |
| Anabolic steroids | Oral, inject | C (not illegal for personal use) |
| Khat | Oral | C |
| Poppers | Sniff | It is an offence for anyone other than a licensed outlet, such as a pharmacist, to supply amyl and alkyl nitrite. Other types, e.g. butyl nitrite and isobutyl nitrite, are currently legal to possess and supply. Covered by the 2016 Psychoactive Substances Act |
| Glue | Sniff | It is an offence to supply these if it is likely that the purpose is abuse |
| Gas | Sniff | |

*Source*: The 1971 The Misuse of Drugs Act, HMSO, London (http://www.legislation.gov.uk/ukpga/1971/38/contents).
The 2005 Drugs Act amendments: http://www.opsi.gov.uk/acts/acts2005/ukpga_20050017_en_1\
***** In October 2018 – the UK Government announced that medicinal cannabis is legal and that patients can be prescribed medicinal cannabis by specialist doctors from 1 November 2018.

As Figure 3.1 showed, the 'burden' of disability-adjusted life years attributed to the use of **illicit drugs** is significantly less than that attributed to alcohol, smoking, or even to physical inactivity (see Chapter 4 ☛). The figures in terms of prevalence of use are also small in comparison to alcohol or tobacco prevalence; however, the mere mention of illicit use of drugs (some legally obtained e.g. valium, some not e.g. heroin) can cause anxiety in teachers, parents, the police, the government, and in young people themselves.

illicit drugs

includes illegal substances, but also legal substances that are used in ways other than intended e.g. sniffing glue, injecting valium.

Why is so much negative feeling attached to illicit drug using behaviour? In part this can be explained by perceptions of such drug use which are driven by one of two models – a dependence model where illicit drug users are thought to be addicted, possibly ill and out of control; or a criminal model, where they are seen as irresponsible, delinquent and even dangerous. These views have influenced how dependency has been treated and the treatments offered to those expressing a desire to stop (see later).

The method of ingestion, perhaps more than the substance itself, has led people to associate some forms of drug use – primarily injecting drug use – with serious diseases including HIV and Hepatitis C. A global systematic review estimated that, worldwide, approximately 15.6 million people (range 10.3 to 23.2 million depending on the report) aged between 15 and 64 years inject drugs, a fifth of whom will be female. The injected substance primarily (approximately 83 per cent) will be an opioid (Degenhardt et al., 2017). Opioid users account for over half of those globally with a drug use 'disorder' or dependence; cannabis dependence accounts for approximately a quarter (Ritchie and Roser, 2019). In Degenhardt and colleagues' review, approximately 17.8 per cent have an HIV diagnosis (Degenhardt et al., 2017) with other reviews noting that more than half of those injecting drugs will have Hepatitis C (Aceijas and Rhodes, 2007; United Nations Office on Drugs Crime, 2014).

## Why do people initiate potentially addictive substance use behaviours?

Smoking, drinking and substance use are generally adopted in youth. For example, the Norwegian Longitudinal Health Behaviour Study of over 1,000 participants followed from age 13 to age 30, found that smoking rates increased from 3 per cent to 31 per cent between age 13 and 18 (Tjora et al., 2011). There are a significant number of young people smoking and accumulating lung and airway damage, or drinking and promoting liver damage that will, for many, create significant health and social problems in the future. It has long been known that there is an increased risk of lung cancer in those that initiate smoking in childhood (about 66 per cent of smokers start before aged 18 years, 40 per cent before aged 16, (ONS, 2012)) as opposed to in adulthood (about a third of smokers actually start smoking in early adulthood (19+ years)). However, with regards to drinking there is also evidence that for older age groups (over 55 years), about a third of those drinking at harmful levels reached such levels later in life (Royal College of Psychiatrists, 2012).

In health psychology texts when presenting broad descriptions of health behaviour (such as here and in Chapter 4 ☛), it is typical to focus on the demographic factors (age, gender, culture, etc.) and on the individual beliefs and attitudes, and forget about the underlying personality traits that potentially interact with these other factors. We therefore will address these also. Firstly though we look to often neglected wider influences: culture and social policy. These are extremely important in predicting individual behaviour. Consider, for example, Finland, where their previous strict legislation on alcohol sales and consumption was liberalised in the mid-1970s and where cirrhosis deaths showed subsequent increases in the 1980s and 1990s. Similar legislative effects can be seen in the UK, where examination of the effects of the 2006/07 smoking ban on smoking cessation has revealed evidence of a downturn in prevalence, particularly among females, partly ascribed to this legislative change (Katikireddi et al., 2016). Benefits to child health are expected to show more over time (Britton, 2016). The impact of such bans on specific subgroups of the population, for example, younger children being exposed less to parental smoking and modelling and the interaction of this with socioeconomic status is currently being examined in secondary analysis of UK data from the British Household Panel Survey and the Understanding Society study 1994 to 2016 (Anyanwu et al., 2018).

As described in Chapter 2 ☛, socio-economic correlates and predictors of initiating risky health behaviour exist, which some refer to as 'distal' or more 'macro' factors (e.g. Tjora et al., 2011). The reasons why generally young people start to smoke, drink alcohol, or take illicit drugs are, as with most social behaviours, many and varied, with the reasons given for each of these behaviours showing a significant degree of overlap. In a journal editorial summarising four independent reviews of factors associated with the behaviours of smoking, binge drinking, healthy diet and physical activity, Conner and Norman (2017) note that environmental factors emerged relevant to binge drinking, and socio-economic status and gender emerged in relation to smoking, with both behaviours also influenced by impulsivity, social influence, motivational and attitudinal influences. Such commentary usefully highlights that while different health behaviours may share some causal influences, each may also have unique influences. We return to this point again in Chapters 4 and 5 ☛.

Several key factors related to initiation are:

- *Genetics*. There is some evidence of genetic factors and the reception and transport of the neurotransmitter dopamine being involved in smoking initiation and possibly its maintenance, but it is unlikely that any genetic influences function in isolation (Munaf and Johnstone, 2008). Genetic factors may also influence a propensity for 'impulsivity' or 'risk-taking' (Kreek et al., 2005; Stautz and Cooper, 2013).

- *Curiosity*. Curiosity is a commonly cited reason for having that first drink of alcohol, first cigarette, or first joint of cannabis (Hecimovic et al., 2014). Wanting to know what 'it tastes like', 'how it feels', usually occurs when others have talked about the behaviour or been observed doing it (see Modelling).
- *Modelling, social learning and reinforcement.* Family behaviour and dynamics are important socialisation processes. Observing certain behaviour, such as smoking, in parents increases the 'preparedness' of their children towards the behaviour by establishing positive attitudes towards it and by possibly reducing perceptions of risk (Tjora et al., 2011). Add to that the presence of smoking or drinking peers and this preparedness is more likely to turn into action. Children with peers (actual friends or even simply desired friends, elder siblings or parents who smoke or drink alcohol around them are more likely to imitate such behaviour than children not exposed to such models (e.g. Mercken et al., 2007, 2011). Siblings are perhaps even more influential than peers, whether through modelling, or through perceived or actual pressure.
- *Peer/social pressure*. Peer/social pressure, where substance use behaviour is positively encouraged (including portrayal in the media/TV) and reinforced by the responses of significant others, has commonly been cited as a reason for their initiation, reflecting either social contagion or influence that a person conforms to (see 'conformity motive' in 'Research focus'). Motives given for cannabis use often include reasons of socialisation, with or without overt pressure (e.g. Hecimovic et al., 2014, see 'Research focus'). Interestingly, Denscombe (2001) reported that people aged 15–16 years rejected the idea of 'peer pressure' being responsible for their smoking initiation, preferring to see it as something they selected to do themselves. This fits with the notion of smoking initiation being tied up with seeking reputation and status.
- *Image and reputation* is important during adolescence. Some theorists suggest that a significant amount of adolescent behaviour is motivated by the need to present oneself to others (primarily peers) in a way that enhances the individual's reputation or social identity (Emler, 1984). Wanting to 'fit' in, to be seen to be sociable (for drinking alcohol perhaps more so than smoking or illicit drug use) and to have status within one's social group are considered important to social functioning (Snow and Bruce, 2003; Stewart-Knox et al., 2005). In some social groups the 'reputation' that will help the individual 'fit' will involve risk-taking behaviours.
- *Self concept andself-esteem.* Studies of adolescent girls have pointed to the importance of self-concept (i.e. concept of what one 'is') and self-esteem (i.e. concept of one's 'value' or 'worth') in determining involvement or non-involvement in risk behaviours such as smoking (Snow and Bruce, 2003).
- *Weight control.* Weight control has been identified as a motive for smoking initiation and maintenance more often among young girls than among young males although males are not immune from this strategy (Fulkerson and French, 2003). In this American study, Native American and Asian American males cited weight control as a reason for smoking more often than males from other ethnic groups, highlighting the need to consider cultural as well as gender variation when examining or comparing national statistics. In a large study of over 4,000 American adults aged 18–29 years a question examining expectancies around smoking and weight ('Smoking cigarettes helps people keep their weight down') found that underweight (41.2 per cent) and normal weight (40.6 per cent) participants were more likely to agree or strongly agree with this statement than overweight (35.7 per cent) and obese (28.3 per cent) participants. (Coa, Augustson and Kaufman, 2018). This supports other findings that individuals with lower BMIs are more likely to be weight concerned. In contrast, alcohol is calorie dense and can contribute to weight gain and so this rather than being a factor cited for initiation, may be given as a reason for cessation.
- *Risk-taking propensity.* Smoking, under-age drinking, and the first use of an illicit drug, typically cannabis, has been found to be a common feature of those engaged in a larger array of 'risk-taking' or problem behaviour, including truancy and petty theft (Johnston et al., 2009). Several disinhibitory-based traits have been associated with risk-taking in terms of substance use behaviours (e.g. Stautz and Cooper, 2013;

Collado et al., 2014) but, as we discuss below, such factors (and any influence they have) may change over time.

- *Health cognitions*. Many smokers, drinkers or substance users report expectancies of stress relief, anxiety reduction or other benefits to the behaviour. Users also often hold 'unrealistically optimistic' beliefs regarding the potential for controlling their behaviour and avoiding any negative health consequences: e.g. 'drinking will give me confidence', 'cannabis use will reduce my anxiety' or 'I won't smoke (tobacco, cannabis) as heavily as other people, so it won't affect my health' (see Chapter 5 ☛ for full coverage of health cognitions).
- *Stress and other comorbidity.* Stress is often cited as a factor in the initiation (and maintenance) of substance use, including smoking. For example, in a large longitudinal study of Australian adolescents (Byrne and Mazanov, 2003), non-smokers at baseline who reported having experienced stress in an intervening year were more likely to become smokers than non-stressed non-smokers. For boys, smoking uptake was only weakly associated with school-related stress whereas for girls, smoking uptake was associated with higher stress from attending school, family conflict, parental control, and perceived educational irrelevance. These perceived stressors distinguished those girls who started smoking from those who did not. The National Longitudinal Study of Adolescent Health has also pointed to a role of depressive symptomatology in smoking onset (McCaffery et al., 2008).
- *Environmental and economic factors.* The direction of effects of economic hardship on substance use varies from findings of higher use among long-term unemployed to longitudinal studies reporting reduced smoking and alcohol consumption where finances are limited, but with most reporting the former (see review by Henkel, 2011). Low parental socio-economic status has also been positively associated with smoking initiation in their adolescent offspring (Tjora et al., 2011). Adding to the complexity of influences on alcohol use, a recent American study using the large Framingham Heart Study Offspring Cohort datasets of 1971–2008 found that unemployment affected consumption levels of women more than men, even when the unemployment was in the male spouse and not themselves (Arcaya et al., 2014).

## Continuing unhealthy behaviour and developing dependency

Global estimates are that around 1.4 per cent of the population (of 7.6 billion) have an alcohol use disorder, and while this may seem low, it is worth noting that this amounts to around 11 million people who are alcohol dependent (WHO, 2018)! As only a small proportion of those who drink alcohol become dependent on alcohol (perhaps one in ten), it is necessary to remember that it is not the case that all alcohol-related problems arise from situations of dependency: in fact the majority do not.

In relation to other drugs it has been estimated that globally around 0.9 per cent of the global population had a drug use disorder in 2017 (excludes alcohol and tobacco), with some variations by country and by age – for example globally the above figure rises to 2 per cent among those aged 20–29 years (IHME Institute of Health Metrics and Evaluation, 2017, Global Burden of Disease; GBD 2019 Risk Factors Collaborators, 2020).

### What is meant by dependence?

Substance use behaviour is generally considered as meeting the definition of a diagnosis of dependence typically if three or more of the following have been present together at some time during the previous year:

(a) a strong desire or sense of compulsion to take the substance;

(b) difficulties in controlling substance-taking behaviour in terms of its onset, termination, or levels of use;

(c) a physiological withdrawal state when substance use has ceased or been reduced, as evidenced by: the characteristic withdrawal syndrome for the substance; or use of the same (or a closely related) substance with the intention of relieving or avoiding withdrawal symptoms;

(d) evidence of tolerance, such that increased doses of the psychoactive substance are required in order to achieve effects originally produced by lower doses (clear examples of this are found in alcohol- and opiate-dependent individuals who may take daily doses sufficient to incapacitate or kill nontolerant users);

(e) progressive neglect of alternative pleasures or interests because of psychoactive substance use, increased amount of time necessary to obtain or take the substance or to recover from its effects;

(f) persisting with substance use despite clear evidence of overtly harmful consequences, such as harm to the liver through excessive drinking, depressive mood states consequent to periods of heavy substance use, or drug-related impairment of cognitive functioning; efforts should be made to determine that the user was actually, or could be expected to be, aware of the nature and extent of the harm.

*Source*: Defined by the IHME based on the definition within the WHO's International Classification of Diseases (ICD-10), Ritchie and Roser (2019).

Physical dependence on a drug, whether legal or illegal, is most commonly considered present when c) and d) are present (i.e. when an individual develops tolerance to a substances effects and therefore more consumption is needed to attain either the same effects or to avoid the withdrawal effects that follow a reduced bloodstream level of the substance). Withdrawal effects are seen in both physical symptoms (e.g. cravings, insomnia, sweating, increased appetite) and psychological symptoms (e.g. anxiety, restlessness, irritability). In this way, drug use can become self-reinforcing as individuals seek to avoid these symptoms. Some individuals report that they deliberately relapse during an attempt to quit a substance in order to get rid of withdrawal symptoms, which are distressing them and also those around them. Resuming the behaviour then acts as a reinforcer in that the person avoids any further withdrawal symptoms, and in this way a vicious cycle emerges.

As with smoking or regular use of alcohol, it is also not the case that the use of all illicit drugs leads to dependency. One example of this is recreational ecstasy use, which is unlikely to lead to dependence, although there are health risks attached to use. Research has long sought to distinguish individuals who maintain safe levels of drinking or substance use from those who develop problem drinking or substance dependency. The main aspects considered have included genetics and family history, with a positive family history for alcohol and drug use disorders being the best known risk factor (Acheson et al., 2017). It is hard to separate out heredity from socialisation influences, and it is likely they combine to influence behaviour. Supporting this, using data from the large Family Health Patterns project comparing family history +ve (FH+) adults from family history –ve adults (FH-), a phenotype was identified which differentiated the two FH groups, but furthermore could predict the odds of an FH+ individual having an alcohol or substance use disorder. This comprised of traits including internalising emotions of neuroticism and depression (for alcohol but not other substance use), exposure to early life adversity, and externalising traits of lower impulse control and higher antisocial tendencies, and not the expected demographic characteristics of lower intellect, education and socio-economic status.

The pre-existence of certain psychopathology, certain mood or personality risk factors, including those of anxious **predisposition**, sensation-seeking or risk-taking propensities, have also been highlighted elsewhere (e.g. meta-analysis of sensation-seeking and alcohol use by Hittner and Swickert, 2006; Woicik et al., 2009, Substance Use Risk Profile Scale). In addition, ADHD and also bipolar disorders were found to be risk factors for developing substance use disorders in a ten-year follow-up study of a large adult cohort (Swendson et al., 2010).

Certain characteristics, and their influence may however change over time (Morrison, 2003). This is seen in a study of adolescents followed annually for five years from early adolescence (9–13-year-olds) to age 13–18 years (Collado et al., 2014) where the developmental trajectories of disinhibitory factors often associated with the onset of health-damaging behaviours, such as sensation-seeking, risk-taking propensity and impulsivity were examined. Contrary to expectations of stability in such "trait" factors over time, interesting differences emerged:

- *Sensation-seeking* scores did not change between Waves 1–2 (i.e. year 1–2) but increased between Waves 2–3, 3–4 and 4–5 in a linear fashion with age, with the greatest increase among non-Black participants There was no overall association with gender.
- In contrast, *risk-taking propensity* increased relatively steeply from Wave 1 onwards, but levelled out between Waves 4–5, with no gender or race effects.
- *Impulsivity*, assessed only from Wave 2, did not change between Waves 2–3, or 3–4 where it peaked (aged 13–17), and then it decreased in the Wave 5.

predisposition

predisposing factors increase the likelihood of a person engaging in a particular behaviour, such as genetic influences on alcohol consumption

The authors interpret some of these differences by pointing out that where sensation-seeking is more a goal-directed construct (purposively seeking new or positive sensations and experience), impulsivity and risk-taking propensity are more related to behavioural control (or lack of!). The stabilisation of impulsivity and risk-taking may reflect age-related developments in neurologically mediated cognitive control (maturation of the prefrontal cortex, see Yurgelun-Todd, 2007). Prospective study is required where risk behaviours are studied over time simultaneously with those disinhibitory variables, something Collado's team do not do. However, what their findings do suggest is that, if such 'personality aspects' naturally change over time, there are implications for the timing of any behaviour change interventions, e.g target-ing sensation-seeking in 15+ year olds.

Such evidence of changes in the influences on behaviour sits comfortably with the weight of evidence that supports social learning theory, i.e, substance use or dependence are considered as a socially acquired and learned behaviour that has received reinforcement (internal or external, physical, social or emotional rewards). In addition, low family cohesion has also been associated with higher levels of drinking-related problems among adolescents. For example, the large (<10,000 participants), American, National Longitudinal Study of Adolescent to Adult Health, suggested that family cohesion may be particularly protective against alcohol-related problems among White American adolescents (Reeb et al., 2015). It may be that where parental or familial relationships are disrupted or weaker, peers gain a stronger influence upon younger people. However, receiving reinforcement for sensation-seeking or impulsive behaviour from other people may diminish with age and maturation which may lead to a downturn in the behaviour. Countering this, receiving reinforcement from an internal source may maintain the behaviour independent of age, i.e. repeatedly seeking the pleasurable and reinforcing physiological, behavioural, or social effects of the substance itself or taking a substance to avoid negative effects of withdrawal may lead to dependence.

Drinking alcohol differs from smoking here in one key way – for *most* people drinking alcohol does not become a daily occurrence and remains casual or social, whereas few people succeed in remaining casual or social smokers. The addictive potential of smoking arises from the biologically addictive properties of smoking. The active ingredient is the alkaloid nicotine, which acts as a brain stimulant, activates 'reward pathways' involving the neurotransmitter dopamine in the brain to release our natural opiates, beta-**endorphins**, thus perpetuating the need to repeatedly intake nicotine to avoid 'withdrawal' symptoms (Jarvis, 2004).

In spite of clear evidence of physiological addiction to nicotine and other drugs including opiates, people who continue to use such substances typically also report psychological reasons for continuing such as:

- pleasure or enjoyment of the behaviour and its mood enhancing effects reinforces positive attitudes towards it (O'Leary et al., 2017).
- a form of stress self-management, a method of emotion regulation, anxiety control for example (Ferrer and Mendes, 2018, see also 'Research focus'); stress has been associated with the maintenance of adult substance use, but little work has explored this association in adolescence, although as noted above there is some evidence of stress being associated with smoking initiation.
- a lack of belief in their ability to stop the behaviour; this belief, often referred to as self-efficacy is discussed in Chapter 5 ☛.
- In addition, behaviours can become 'simply a habit'. Habit formation is a critical barrier to behaviour change. While habit could reflect psychological and/or physical dependence, the point is that the behaviour has become 'conditioned' to external (as well as any internal physiological cues or craving), such as the cigarette on the drive into work, or with a coffee (see Chapter 5 ☛).

Cox and Klinger (2004) describe a motivational model of substance use based on consistent findings that people's decisions about substance use are not necessarily rational but involve a complex range of motivational and emotional components and depend also on the rewards and incentives received from the behaviour. We address

**endorphins**

naturally occurring opiate-like chemicals released in the brain and spinal cord, they reduce the experience of pain and can induce feelings of relaxation or pleasure; associated with the so-called 'runner's high' motivational and emotion regulation factors in 'Research focus'. In relation to rewards and incentives, a person considering their smoking, drinking or drug use may do so in relation to other aspects of their lives that they may or may not derive satisfaction from. Individuals without commitment to healthy life goals or the motivation to work towards attaining them are less likely to perceive their substance use as a problem and consider themselves as less able to change the behaviour. Of course, the reasons for continuing to smoke, drink or take other drugs are not necessarily the same as reasons given for initiation, and patterns of the behaviour, and influences on it, may also change over time. While some of the original reasons for a behaviour may persist, e.g. smoking or drinking for relaxation, other factors, including dependence, may emerge to maintain it. All contributing factors need to be understood in an appropriate context if efforts to cease the behaviour are to succeed.

## Behaviour cessation

Smoking cessation increases with age, higher education and less time spent smoking. A study of predictors of cessation over a period of 12 years among 4,636 smokers from seven centres in Northern Europe confirmed this, plus reported that few health conditions (including chronic respiratory conditions) had an impact on cessation (Holm et al., 2017). This latter finding is surprising given that even people who stop smoking when aged between 50 and 60 can avoid most of their subsequent risk of developing lung cancer or other smoking-related disease or disability such as Chronic Obstructive Pulmonary Disease, coronary artery disease, or stroke. Quitting at 55 can gain a male on average five life years (based on 50 years of follow-up of a sample of British male doctors, and better still, stopping when aged 30 leads to approximately ten life years gained (Doll et al., 2004). While very old smokers may be less likely to try to stop smoking, there is some suggestion that they are more successful when they do (e.g. Ferguson et al., 2005).

Attempts to help people to stop smoking are generally viewed positively by the public, and in fact the majority of smokers themselves will report that they wish to stop smoking. However a review of predictors of cessation in a general population of adult smokers (Vangeli et al., 2011) found that while motivational factors and previous attempts to stop smoking were predictive of further attempts to stop, they were insufficient to explain *successful and maintained* cessation. Although findings are inconsistent it is fair to say that social as well as individual factors play a role. In addition, while emotion regulation (managing negative emotions, including coping with stress), is often cited as a reason for uptake of risk behaviours, other research suggests that quitting smoking actually reduces stress (West and Shifman, 2016; West, 2017).

In relation to alcohol consumption, a recent review (Kuntsche et al., 2017) concluded that increasing the price of alcohol (through minimum pricing legislation or increased taxation) was the most effective policy instrument to reduce alcohol consumption at a population level. West also concluded in a review published in the same issue (West, 2017) that for every 10 per cent increase in the cost of a pack of cigarettes there is a corresponding 4 per cent decrease in the number of cigarettes purchased.

Yet, prices may not be so influential on smoking cessation as they are on prevalence – for example, it has been reported that stopping smoking is more likely among individuals of a higher socioeconomic status. Cessation is also more successful in those with a higher level of education (Holm et al., 2017). This may reflect differing levels of knowledge and understanding about potential health consequences, or it may be that successful quitters also have fewer smoking acquaintances and friends than non-quitters and that is socio-economically influenced also. Various studies have shown the importance of smoking and non-smoking networks to quitting attempts and successes, whereby not being part of a smoking network facilitates cessation (e.g. Blok et al., 2017). Barriers to cessation, including for some, a fear of weight gain (Pisinger and Jorgensen, 2007), are considered in Chapter 5 ☛. Chapters 6 and 7 ☛ describe interventions aimed at promoting smoking cessation.

## Thoughts about treating dependence

Societal views of substance use disorders, which by definition include alcohol and illicit drugs (prescribed or not) but not tobacco, or drug dependence (excludes alcohol and tobacco) (as defined by the WHO International Classification of Diseases ICD-10) have changed over time. In relation to alcohol and opiate taking, perspectives have shifted from viewing dependence as the immoral behaviour of weak individuals, unable to exert personal control over their consumption during the seventeenth–eighteenth

## RESEARCH FOCUS

### Emotion, motives and health behaviour

Hecimovic, K., Barrett, S.P., Darredea, C. and Stewart, S.H. (2014). Cannabis use motives and personality risk factors. *Addictive Behaviors*, 39: 729–732.

O'Leary, D., Suri, G. and Gross, J. (2017). Reducing behavioural risk factors for cancer: an affect regulation perspective. *Psychology & Health*, 33:17–39

This Research Focus raises points highlighting the importance of personality, emotion and motivation which is relevant to this chapter's discussion of health risk behaviour but is also relevant to discussion of health-enhancing behaviour (Chapter 4 ☛), to discussion of models of theories of health behaviour change (Chapter 5 ☛) and to discussion of interventions (Chapters 6–7 ☛). The keen student could usefully explore further some of the studies cited in each article. The emotional context in which decisions are taken around health or risky behaviour is, like personality, often given less consideration than other factors such as individual beliefs and expectancies (Ferrer and Mendes, 2018) (see Chapter 5 ☛).

In the first study, focusing solely on cannabis users, Hecimovic and colleagues found that different personality factors related to different *motives* for the cannabis use, i.e. the reasons given for using cannabis varied according to the extent to which the individual user scored on four personality 'risk' factors (two of which were mentioned above): sensation-seeking (SS), impulsivity (IMP), introversion/hopelessness (I/H), and anxiety sensitivity (AS). While the sample varied in the frequency of cannabis use, all participants reported their motives for use using a 29-item motive scale, which was then factor analysed to produce four factors:

> 'Enhancement motives' i.e. to have fun; to enjoy the feeling;
>
> 'Expansion motives' i.e. to see things differently, to be more creative;
>
> 'Conformity motives' i.e. to fit in with peers, to help socialise; and
>
> 'Coping motives' i.e. as an escape, to forget about problems.

SS was significantly and positively associated with Expansion motives; AS was significantly and positively associated with Conformity motives and negatively and significantly associated with the Expansion motives (with a trend also towards association with Coping motives); and I/H was significantly and positively associated with Coping motives. Impulsivity overall was not associated with any of the four factors, but on analysis by item, impulsivity was significantly higher in those who endorsed the motive for cannabis use as 'because it was easier to get than other drugs' i.e. suggesting an availability motive.

These findings confirm previous evidence of substance use and coping motives but highlight that this may be a stronger motive in those of a certain character, i.e. those who are introverted or have an anxious predisposition. Impulsive individuals by definition show less specific planning of behaviour, having more erratic motives perhaps, and hence why availability may simply create a tempting environment for impulsive folk. Notable is that those high on anxious sensitivity also reported using cannabis to conform and perhaps to reduce social anxiety.

Our affect, or mood, and how it is judged to be positively affected by a certain behaviour, for example cannabis use in the above study, is one factor contributing to people continuing to smoke cannabis, or conversely, engaging in positive health behaviour such as exercise, i.e. people continue the behaviour because they enjoy it (see Chapter 4 ☛, van Cappellen et al., 2017). However, it is clear that positive affect arising from behaviours that carry risk to health, such as smoking, drinking, illicit drug use and overeating, presents a challenge to efforts to cease the unhealthy behaviour, e.g. 'If I stop smoking how will I reduce my stress?'; 'If I stop smoking cannabis I will miss the happy feelings.'

As we have pointed out, nearly half of all cancers have preventable, mostly behavioural causes and therefore understanding why people engage in these behaviours is critical in order to inform interventions. The second paper introduced here reviews health behaviours from both an affect regulation (AR) perspective and a stress-coping perspective and proposes a model of risky health behaviour that highlights the joint and integrated role of these two theoretical approaches – two areas typically examined separately (see Chapter 11 ☛). Firstly O'Leary, Suri and Gross (2017) review evidence that three cancer risk behaviours – tobacco use, alcohol use, and overeating – 'can be understood as a form of AR, both in terms of increasing positive affect and in terms of decreasing negative affect' (p. 18). Evidence exists in this regard for all three behaviours. For smoking, although the focus has been more on how it reduces negative affect, i.e. helps people cope with stress or to relax, positive affect or increases in alertness are also given as motives for smoking and attributed to the physiological effects of nicotine. For drinking alcohol the focus has been on attaining positive affect, perhaps the sedating effects are calming but people also report drinking to remove negative mood and as a means of stress management. Perceived stress has been found to immediately precede drinking, including binge drinking. For over-eaters, both increasing positive affect and reducing negative affect are provided as reasons for the behaviour. Tasty, calorie-dense food activates the brain's reward systems in a similar way as do alcohol and nicotine (role of dopamine) (see Chapter 8 ☛) and for 'reward-sensitive' individuals eating can become motivated more by emotion than by hunger. Equally, low mood often precedes binge eating, and both acute and chronic stress exposure do likewise. Obese individuals, binge eaters or emotional and restrained eaters are particularly prone to eating to reduce negative affect or to reduce stress.

Given the reviewed evidence, O'Leary and colleagues go on to propose an integrated model of affect regulation, drawing from Lazarus's stress and coping literature (see Chapter 11 ☛ and the emotion regulation literature (Gross, 2015)). In this way stress responses and emotions are considered as two sub-types of affect. Rather than pre-empt a large part of Chapter 11 ☛, the critical point here is that O'Leary highlights the critical role played by a person's beliefs – their appraisals of internal and external events that may be stressors – and their belief that a certain way of coping will help them manage those stressors. Coping can target the emotional response to the stressor – the affect – or it can target the stressor/the problem itself. Combine this with paying attention to how one feels and an appraisal of the emotions as being harmful or unpleasant, and a belief that drinking alcohol, smoking a cigarette or a cream cake, will help alleviate those feelings, and you can begin to see clearly how stress appraisal, coping and emotion regulation can concurrently affect behaviour. The ER literature addresses a wide array of emotions, both acute, short-lived emotions, for example, frustration, and longer term chronic affective states, for example depression.

The model proposed identifies a first-level valuation system that identifies whether there is a gap between an individual's perception of the current state of their world and where they would like it to be – and if there is a gap, whether they want to take action physically or psychologically to address it and if so, what action they believe will fill this gap. The goal then is part of a second level evaluation, i.e. they have identified an affect they want to regulate (e.g. anxiety) and need to decide how they are going to implement the necessary action. Success or failure of the selected action is determined on the basis of whether the negative affect is removed, or the positive affect is achieved.

Critical to the success of affect regulation is the ability to recognise/identify one's affective states as being undesirable or atypical – some people however may be overly sensitive to occasional feelings of sadness for example, and may engage in maladaptive Affect Regulation by drinking alcohol. Conversely, other people may overemphasise the importance to their life of a positive affective state and be motivated by the associated feeling of reward/gain which may also lead to unhealthy behaviour. Choosing drugs to regulate a perceived negative affect rather than using distraction, for example, highlights selection differences in coping responses. Of course, if the substance use behaviour succeeds in achieving the goal of reduced anxiety, for example, then it will maintain that behaviour as a choice for the next time anxiety or another negative affect is experienced.

Social learning provides a strong theoretical and empirical explanation for alcohol and other substance abuse, as does emotion regulation. It is noted that those with

*(continued)*

substance use or eating disorders such as bingeing report fewer adaptive emotion regulation strategies. Also relevant here is a belief that one can do what is required to manage/regulate negative or positive affect to one's benefit – and this construct appears on many occasions in this textbook in relation to other behaviours – self-efficacy. If positive ER strategies, for example turning to someone for support during times of depression, seem difficult (for a variety or personal, social or cultural reasons), then a maladaptive strategy, such as drinking, may be selected instead.

The O'Leary paper continues to consider their Affect Regulation model in relation to carrying out chosen coping responses of maladaptive health behaviours and the monitoring of their effects on affect. It also details some of the experimental, methodological and assessment issues research should consider if the integrated model is to be taken further, including the need to examine individual and group differences and their effect on all stages of the Affect Regulation model.

## Things to think about and research yourself

We have highlighted here that our personality likely influences our motivations to carry out certain risk behaviours; likewise our affect/mood can influence initiation of behaviours. It is demonstrated that some behaviours achieve emotion regulation, e.g. drinking is reported to reduce social anxiety, smoking cannabis likewise – and thus ER is a likely factor in behaviour maintenance.

How might some people interpret these kinds of findings – is there any value in intervening with personality? Would interventions not more effectively target emotions or motivations? If a health-damaging behaviour is thought to serve a beneficial affect regulation purpose, what will take its place if it is ceased?

What would you target if you recognised someone as being of a highly anxious predisposition? Think about these factors also while reading later chapters addressing interventions.

centuries, to being the behaviour of passive victims of an evil and powerful substance in the nineteenth century. The earlier 'moral' view considered individuals as responsible for their behaviour and therefore the ethos of treatment was punishment. The latter view considered the individual to have less control over their behaviour, and as such the Prohibition of alcohol sales in the early twentieth century (as seen in the USA 1920–1933) was considered an appropriate societal response. Treatment was offered to 'victims' who 'succumbed' and this medical treatment of individuals with alcohol problems reflects the beginnings of a disease concept of addiction. However, when it became clear that prohibition had failed the model of alcoholism developed into one that placed responsibility back onto the individual. In 1960, Jellinek described alcoholism as a disease but considered both the nature of the substance and the pre-existing characteristics of the person who used it (Jellinek, 1960). While it became accepted that alcohol could be used by the majority without any resulting harm, a minority of individuals developed alcohol dependence, and for these individuals pre-existing genetic and psychological 'weaknesses' were still acknowledged. Addiction was seen as an acquired, permanent state of being over which the individual could regain control only by means of abstinence. Treatment reflected this, for example, the self-help organisation, Alcoholics Anonymous, founded in 1935, had the primary goal of helping individuals to achieve lifelong abstinence.

However, in psychology during the early twentieth century, the growth of **behaviourism** brought new methods of treatment for those with addiction problems that drew from the principles of **social learning theory** and **conditioning theory**. These perspectives consider

**behaviourism**
the belief that psychology is the study of observables and therefore that behaviour, not mental processes, is central

**social learning theory**
a theory that has at its core the belief that a combination of outcome expectancy and outcome value will shape subsequent behaviour; reinforcement is an important predictor of future behaviour

**conditioning theory**
the theory that behaviour is directly influenced by its consequences, positive and negative

behaviour to result from learning and from the reinforcement that any behaviour receives as we have discussed earlier in this chapter. If excessive alcohol consumption has been 'learnt' then according to these theories, it can be 'unlearned'. By applying behavioural principles to treatment the aim would be to identify the cues for an individual's drinking or drug use behaviour and the type of reinforcement individuals receive for it (see Chapter 6 ☛). Such approaches therefore do consider the individual, their behaviour and the social environment. Nowadays, abstinence is considered as only one possible treatment outcome among others, such as controlled drinking or opiate replacement therapies (e.g. methadone programmes). In controlled drinking, individuals are encouraged to restrict their consumption to certain occasions/settings/times of day, or to control the alcoholic content of drinks consumed by, for example, switching to low-alcohol alternatives.

Health promotion efforts therefore have two targets: **primary prevention** in terms of educating children about the risks of smoking, drinking or drug use and about 'safe' levels of consumption; and secondary prevention in terms of changing the behaviour of those already engaged in such behaviours. Examples of these are described in Chapters 6 and 7 ☛.

Whether influenced by personality, cognitive development, peer behavioural norms, reacting to stress or availability, and whether motivated by a desire to escape or regulate negative thoughts, emotions or situations, the prevention of initiation to illicit drug use can and should be treated in the same way as alcohol use or smoking. In terms of reducing use among regular users, for a minority there will be, as with alcohol, issues of physical and psychological dependence to deal with. To a large extent the treatment of opiate dependence can be the same as the treatment for alcohol dependence, at least in terms of any cognitive or motivational therapy and given the social influences thereon (see Orford 2021 for a discussion of common themes supporting 'excessive appetites'). What will differ will have been people's responses to the individuals concerned and how, perhaps, they have been treated by health and social care services. In addition, the illegality of some substance use takes the user into contact with the legal system, and for PWID (people who inject drugs) frequently the prison system and all the ramifications of that. It is not the purpose of this book to do anything more than to raise, for the reader, the question of societal judgement. One example of this can be seen in relation to illicit drug use, particularly opiates which, for many users, are ingested via injection. As an approach to reducing harm to the user, the Advisory Council for the Misuse of Drugs (2016) recommends that increasing the presence of needle-sharing facilities, and even safe drug use centres (supervised drug consumption rooms), around our cities, will go some way towards reducing drug-related deaths from overdoses, and also reduce the likelihood of needle sharing associated with infections such as Hepatitis C and HIV. However, harm reduction approaches do not reduce the behaviour per se and so other approaches are also needed – public health and educational monies need to be invested in increasing knowledge, support and the skills necessary, to assist those at the start of their illicit drug use, and to derive wider social benefit.

primary prevention

intervention aimed at changing risk factors prior to disease development

## Unprotected sexual behaviour

Unlike the behaviours described up to this point, sexual practices are not inherently individual behaviour but fundamentally a 'social' behaviour arising from an interaction between two individuals. (While some substance use may be considered 'social', the actual physical behaviour is typically down to individual action). As such, researchers studying influences on unprotected sexual behaviour and its consequences, and health educators seeking to promote safer sexual practices such as condom use, face particular challenges (see also Chapter 5 ☛). Given the evidence that consistent condom use (defined as use for all acts of penetrative vaginal intercourse) reduced HIV incidence among heterosexuals by 80 per cent, it is worth persevering (Cochrane Review by Weller and Davis-Beaty, 2007).

## Negative health consequences of unprotected sexual intercourse

Notwithstanding unwanted pregnancy, unprotected sexual intercourse carries with it several risks: infections such as chlamydia and HIV. Sexual behaviour as a risk factor for disease has received growing attention since the 'arrival' of the human immunodeficiency virus (HIV) in the early 1980s and the recognition that AIDS affects heterosexually active populations as well as homosexual populations and injecting drug users who share their injecting equipment (Morrison, 1991).

### HIV prevalence and incidence

From around 8 million cases in 1990, the most recent data from WHO and UNAIDS report that approximately 38.0 million people are currently living with HIV/AIDS, of whom roughly 1.7 million are children aged less than 15 years (WHO, 2018b). The increase in availability of medicines that suppress viral replication, typically referred to as highly-active antiretroviral therapy (HAART) is the primary reason for the increase in prevalence, i.e. those living with the disease, and as a result the downturn in deaths. Deaths have reduced by a massive 51 per cent since 2005 – an estimated 690,000 died in 2019 of HIV-related illnesses, compared with 1.9 million deaths in 2005 (UNAIDS, 2020). Noticeably deaths from HIV/AIDS have moved from the world's 8th leading cause of death in 2000 to the 19th in 2019 (World Health Organization 2018, 2020).

Globally the decline in incidence, i.e confirmed diagnoses, is more likely attributed to changes in individual risk behaviours including condom use and reductions in needle sharing among injecting drug users. While around 70 per cent of HIV cases are concentrated in Africa (mainly the Sub-Saharan East and South) (with a 3.9 per cent adult prevalence in Sub-Saharan Africa, compared with an average 0.2 per cent prevalence in Western Europe (0.17 in the UK) and 0.1 per cent prevalence in Central Europe), there is cause for concern in Eastern Europe. In figures published by Avert in 2018 (AVERT, 2018), Eastern Europe accounted for 130,000 out of the 160,000 new HIV diagnoses throughout Europe. Notably, two countries (the Russian Federation and Ukraine) contributed 75 per cent of all cases of newly diagnosed infection in the WHO European Region and 92 per cent of cases in Eastern Europe. Although some of this may be due to increased openness in reporting, this upturn is also attributed to increased 'unsafe' heterosexual sex, and needle sharing in drug users (AVERT, 2019b). At the same time in Western Europe new diagnoses have declined by 20 per cent, primarily attributed to a downturn in infections among homosexual men.

In Western Europe there is reasonable consistency in population prevalence of HIV, with Spain, France, Germany, the UK, Turkey and Italy having higher infection figures, attributed in large part to the prevalence of injecting drug use, although the majority of new infection is still among homosexual men. In contrast, in three Baltic countries – Estonia, Latvia and Lithuania – the majority of HIV transmission arises from injecting drug use and heterosexual transmissions, including those arising from the sex industry. (See more at: AVERT, 2020 and Figure 3.4. for further regional variation). In 2017 (AVERT, 2020) globally new infections were distributed as follows:

- 1 per cent transgender women
- 3 per cent sex workers
- 8 per cent injecting drug users
- 18 per cent gay men and other men who have sex with men
- 18 per cent clients of sex workers and partners of other key populations
- 52 per cent rest of population (heterosexual).

Of these, approximately 150,000 new HIV infections globally were in children aged 15 years or less.

In many countries, unprotected heterosexual sex has largely taken over from homosexual sex and injecting drug use (IDU) as a route of infection, initially appearing to support research findings of behaviour change among homosexual men and of the effectiveness of syringe-exchange schemes for injecting drug users in some countries. Although needle sharing still occurs, in the UK diagnoses of HIV among PWID (people who inject drugs) have shown a steady decline over the past 30 years. However, male homosexually acquired infection continues to account for the majority of new UK diagnoses with some concern that the perceived success of HAART has led to people considering AIDS as less serious and less lethal, thus undermining the implicit requirement to practise safer sex. This may also underlie the worrying upturn in HIV positive diagnoses among

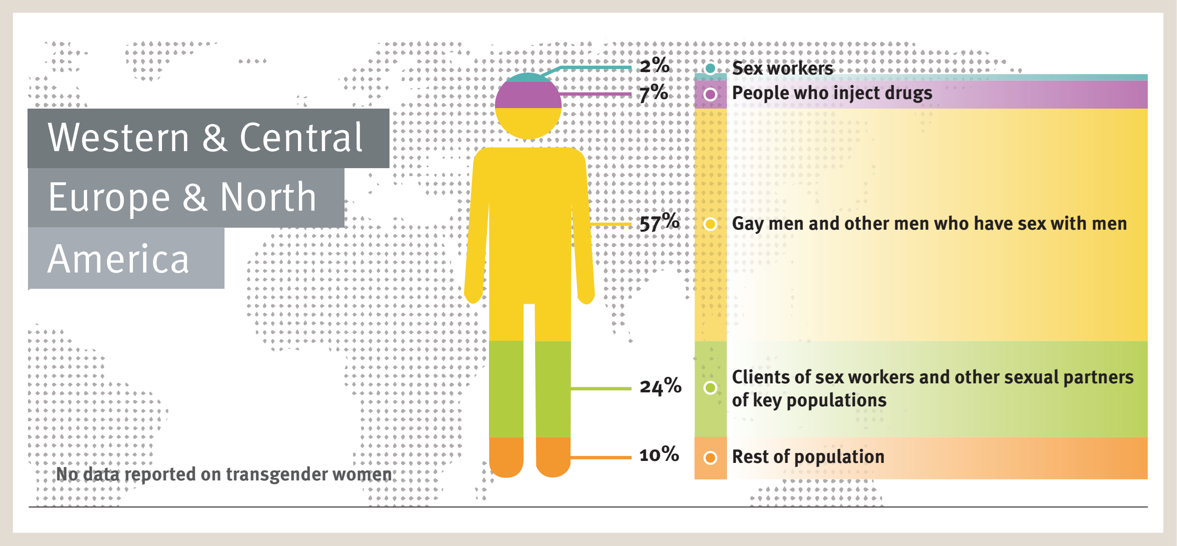

**Figure 3.4** Distribution of new HIV infections among population groups In Western and Central Europe and North America

*Source*: Avert.

PWID in Glasgow (Scotland) between 2015 and 2019, although curiously, in England over the same time period the incidence fell. This suggests that a range of explanations are likely rather than one. For example, in Glasgow it is estimated that 45 per cent of HIV positive PWID are also homeless which compounds issues such as access to services or treatments. (National AIDS Trust, 2018)

Young women are still most likely to be affected by HIV, and globally women aged 15 years + account for almost half (48 per cent) of all cases. Much of this is due to high prevalence among women in Sub-Saharan Africa (59 per cent of all new HIV infections in 2019; UNAIDS, 2020), but nonetheless infection has greater implications for women (as the ‘receptors’ of semen during sexual intercourse) than men (AVERT, 2019). Notably, while UNAIDS data shows that 81 per cent of those found to be HIV positive knew their HIV status, this leaves almost a fifth who did not and who thus were unlikely to be practicing safe sex and reducing transmission likelihood, not seeking out effective HAART.

## Chlamydia, HPV and other sexually transmitted infection

HIV infection is of course not the only STI that can result from unprotected sexual intercourse, with others including chlamydia, genital herpes simplex and genital warts, most common among adolescents and young adults. While infections can be symptomless, some, like HIV and HPV can lead to physical disease. Chlamydia is a curable disease arising from infection with a bacteria, chlamydia trachomatis. Chlamydia is most often notified among young women heterosexuals and is the most preventable cause of infertility; it is estimated that 1 in every 20 sexually active women aged 14–24 years will be infected. Cases across Europe seem to have stabilised, with a rate of around 184 per 100,000 across the 26 EU Member States (ECDC, 2018). Compare this to new cases of gonorrhoea with a much lower overall incidence in 2016 of around 18.8 per 100,000, but with a worrying increase of 47 per cent in confirmed cases since 2012. There is significant between country variation, although, gonorrhea is most often (almost half of all new cases) diagnosed among men who have sex with men, particularly those aged 20–34. Syphilis, also caused by a bacterial infection (Treponima pallidum), is less common across Europe than gonorrhea, with approximately 6 cases per 100,00 population (9.7 per 100,000 in the UK); however there are concerns that diagnoses have increased by 41 per cent since 2012, particularly among men aged 25–34, and more so among men who have sex with men who account for 66 per cent of all cases across Europe, and 79.4 per cent of all UK cases. Genital herpes, caused by the Herpes simplex virus, hit a peak in the UK in 2008, but has stabilised in recent years to an incidence rate of 61.2 per 100,000. Females accounted for 63 per cent of cases, typically aged between 20 and 24 years (incidence 343.4 per 100,000).

A subgroup of a family of viruses, known collectively as Human Papilloma Virus (HPV), have been associated with abnormal tissue and cell growth implicated in the development of genital warts and cervical cancer. New diagnoses of genital warts, which result from HPV infection and are most common in those aged 20–24, lay at around 126 per 100,000 in 2015 which was a drop of almost 9 per cent since the previous year. The significantly reduced incidence in the UK has been attributed to the introduction of the HPV vaccination programme for females in 2008 (Public Health England, 2016) with calls for its extension to young men, also at risk of infection from sex with men or from unprotected women (Sherman and Nailer, 2018).

The high-risk type viruses labelled HPV-16 and HPV-18 together cause over 70 per cent of squamous cell cancers (cancer in flat-type cells found on the outer surface of the cervix), and approximately 50 per cent of adenocarcinomas (cancer in the glandular cells which line the cervix).There are also low-risk type HPV viruses which are associated with the development of genital warts, which do not cause cervical cancer in themselves but which are a sexually transmitted infection which cause significant discomfort. HPV is not contagious as such, but can be transmitted from a single act of sexual intercourse with an infected person. While condom use reduces the risk of infection, HPV 'lives' on the whole genital area and therefore a condom alone is insufficient to prevent transmission. HPV is startlingly prevalent and therefore the discovery of a vaccination against those types of HPV which cause 70 per cent of cervical cancers (but not genital warts) has been billed as a major public health discovery. This is discussed further in Chapter 4 ☛ and in Chapter 5 ☛ where key psychological factors and socio-cognitive predictors of screening uptake are explored.

## The use of condoms

The relevance of providing the detail above becomes clear when one considers the preventative role that could be played by practising 'protected' sex and using condoms. Condom use can protect one from being infected, and also from infecting a partner. Prior to HIV and AIDS, sexual behaviour was generally considered to be 'private' behaviour and somewhat under-researched (with the exception of clinical studies of individuals experiencing sexual difficulties). This made it initially extremely difficult to assess the potential for the spread of HIV infection; however a notable early survey, the National Survey of Sexual Attitudes and Lifestyles, conducted with nearly 19,000 adults (aged 16–59) living in Britain in 1990–91 (Wellings et al., 1994) reported that:

- Young people use condoms more commonly than older people.
- Females tend to use condoms less often than males.
- Condom use is most common with a 'new' sexual partner.
- Condom use declined dramatically in those who reported having had multiple new partners.
- The rate of condom use was lowest in males who had multiple partners who were not new.
- Female condom use was less affected by whether multiple partners were 'new' to them or not.

In subsequent national surveys (e.g. ONS, 2010), condom use remained highest among younger respondents (e.g. 18–24-year-olds) than older groups and among those for whom the last sexual partner was 'new'. More recently, a YouGov survey, conducted with Public Health England (as cited in PHE, 2017) found that almost half (47 per cent) of the >2000 respondents, all aged 16–24 years, did not however use condoms when having sex with a new partner, which raises concerns about risks of STIs. Being consistent in their use is also an issue, highlighted by findings that only 25 per cent of an Australian sample reported using a condom 'in their most recent sexual experiences' (de Visser et al., 2014). The importance of ensuring representation across differing cultural and religious groupings in our research is highlighted by findings of a survey of over 11,000 men and women aged 16–44 years (NATSAL II; Erens et al., 2003) where non-white ethnicity and being of a non-Christian religion was associated with greater condom use. More recently a study of 903 sexually active, unmarried, female migrant workers in China found that only 13.8 percent consistently used condoms (Shen et al., 2019).

People's condom use will be in part shaped by their beliefs, attitudes, expectations and behavioural skills (see also Chapter 5 ☛). The prevention of pregnancy is given as the primary reason for condom use, with, perhaps surprisingly, the perceived risk of catching an STI considered insufficient by many as a reason for their use (PHE, 2018), although there are age differences in this, with those aged 16–24 years mentioning prevention of HIV and other STIs equally or more so than pregnancy avoidance. This may reflect increased awareness of HIV and sexual health, although use levels are still far from optimal (see Chapters 6 and 7 ☛). Safer sex practices are not of course influenced solely by concerns about STIs, but also by the type, number and length of sexually active relationships a person is engaged in. The rate of condom use among those with multiple partners – 'high-risk' individuals – is also generally higher. Condom use commonly begins to decline after six months within any given relationship.

## Barriers to condom use

Many factors have been reported to act as barriers against safer sex behaviour, including considerations of whether the use or non-use of condoms is related to personality. The broad trait of sensation-seeking has consistently been predictive of sexual risk-taking, as has low levels of Conscientiousness (one of the 'Big Five' personality traits – see Chapter 12 ☛) and thus it seems appropriate to examine in the context of condom use. Hagger-Johnson and colleagues (2011) explored the association between personality, drinking, and specific sexual encounters, to examine whether personality had a direct effect on condom use behaviour or whether alcohol use mediated this effect. In other words, does any effect of personality on condom use only operate VIA an effect on drinking behaviour? They found that Conscientiousness directly increased the likelihood of condom use during the most recent sexual event (when recency of event and partner type (casual/main) was controlled for), and did not confirm other reported associations between alcohol consumption and non-condom use. Low Conscientiousness was therefore the risk factor for unprotected sex, not the drinking per se.

Alcohol intake has however been found to reduce condom use in both younger and older individuals, heterosexuals and homosexuals, an effect sometimes attributed to the disinhibitory effects of alcohol, as discussed in a review by Lan and colleagues (Lan et al., 2017). Other contextual factors need also to be considered: for example, while several studies reported effects of implicit and explicit attitudes on condom use in a variety of contexts, a recent experimental study went further by manipulating sexual arousal and assessing its effects on condom use intention and upon explicit and implicit/automatic attitudes towards condoms. Findings revealed that when not aroused, reflective processes involving explicit attitudes predicted condom use intention, whereas when aroused, both explicit and implicit attitudes predicted intention (Wolfs et al., 2017). This study addresses intention however, not behaviour. Models of behaviour that consider the dual process of reflection and impulsivity are described further in Chapter 5 ☛.

Many interpersonal, intrapersonal, cultural and contextual factors have been shown to interact and affect whether or not the woman feels able to control the use of condoms in sexual encounters (e.g. Downs et al., 2017; Shen et al., 2019). While young women share some of the negative attitudes towards condom use found among male samples (such as that condoms reduce spontaneity of behaviour or reduce sexual pleasure), and they also tend to hold unrealistically optimistic estimates of personal risk of infection with STIs, women face additional barriers when considering condom use. These can include

- anticipated male objection to a female suggesting condom use (condom use resistance due to perceived denial of their pleasure);
- difficulty/embarrassment in raising the issue of condom use with a male partner;
- worry that suggesting use to a potential partner implies that either themselves or the partner is HIV-positive or has another STI/STD;
- lack of self-efficacy or mastery in condom use.

These factors go beyond the individual's own health beliefs and behavioural intentions regarding avoiding pregnancy, or STIs; they highlight that sexual behaviour is a complex interpersonal interaction. The promotion of safer sexual behaviour requires multiple-level interventions that target not only individual health beliefs (see Chapter 5 ☛) but also their interpersonal, communication and negotiating skills (see Chapters 6 and 7 ☛).

Individual behaviour, where positively or negatively associated with health, can be a sensitive issue, with some people preferring to keep their practices and motivations to themselves. This creates challenges for those interested in measuring health or risk behaviour. While measurement issues are not confined to studies of health behaviour, they are particularly pertinent in this domain (see 'Issues').

## ISSUES

### The challenge of measuring health behaviour

The research tradition assumes that the objects of study, e.g. health, illness, or in the context of this chapter, behaviour, remain as fixed entities in people's minds. However, without a researcher actually being present and observing the individual behaving over long periods of time, it is difficult to know whether what a person reports to the researcher (or clinician) accurately reflects their actual behaviour. Obtaining valid measures of behaviour is made increasingly difficult when one is interested in behaviour that is perhaps considered 'undesirable' (e.g. excessive alcohol or drug use), or when it is private (e.g. sexual behaviour).

Researchers also face the challenge of knowing how best to define the behaviours under study, and yet it is only through appropriate definition that measurement becomes possible. For example, rather than defining exercise in terms of organised activity, it could be defined as any physical activity that requires energy expenditure; or in terms of drinking alcohol, a 'drink' can be defined and counted in terms of standard 'units' (see alcohol section), by the size of glass, or strength of alcohol. The definition adopted will influence the questions asked. Additionally questions need to address not just the type of behaviour performed but also aspects such as the frequency, duration, intensity, and even the social context in which it is performed. The earlier discussion of binge drinking highlights the importance of such factors, and they are just as important when measuring physical activity (Kelly et al., 2016).

Where direct observation and/or objective measurement (for example, taking blood or urine samples to measure alcohol or drug levels, wearing an accelerometer to measure movement) are not possible, researchers generally rely on *self-report*. When studies are interested in the frequency with which a behaviour is performed, it is typical to ask study participants to complete a diary, for example, of cigarettes/alcohol/foods consumed. Participants in such studies are generally required to either record the relevant activity daily for a period of a week (any longer places high demand on participants), or to reflect back on the previous week's activity (a retrospective diary – RD). The latter has obvious memory demands – could you accurately recall how many units of alcohol you drank over the past seven days? While there is no evidence of a systematic bias towards overestimation or underestimation, the correlation between objective measures (for example blood alcohol levels, or heart rate during exercise) and subjective reports can be quite low (Shakeshaft et al., 1999., Rhodes et al., 2017). Attempts to cross-validate behavioural self-reports by obtaining observer ratings are not always ethical and taking physiological measurements or blood samples can be both intrusive and costly. Also, for some behaviours there are no obvious short-term physiological/objective measures, for example, in relation to healthy diet (de Ridder et al., 2017).

As an alternative to reporting behaviour over a fixed time period, some studies ask participants about their 'typical or average' behaviour: for example, the typical amount of alcohol consumed (quantity), and the 'typical or average' number of days on which they consume alcohol (frequency). This method provides what is known as a quantity/frequency index (QFI). However, when Shakeshaft and colleagues (1999) compared an RD method with a QFI, they found that the RD method elicited higher reported levels of weekly alcohol consumption than did the QFI. In fact, the QFI may provide over-general information, thus neither way may be totally accurate. Some advocate using 'yesterday' as the measurement time frame as a means of minimising underreporting, for example, Stockwell and colleagues, who do so following a comparison of under- reporting of drinking behaviour across 4 English-speaking countries- UK, Australia, Canada, USA (Stockwell et al., 2016),

A further way of minimising inaccuracies in reporting is by using continuous *self-monitoring techniques*, such as wearing recording devices, or completing alcohol or food consumption diaries, with shorter recording periods, e.g. hourly. This can be a useful method of establishing patterns of behaviour and, where diaries are concerned, the circumstances in which they occur. For example, food diaries can be generated using smartphone apps' as well as online, for example with dieting companies such as WeightWatchers®. These tools commonly instruct the person completing them to note not only the time at which each meal or snack is consumed but also the location, whether anyone else was present, whether any particular 'cue' existed and the reasons for consumption. Some studies invite the person to note also their physical activity (Niamark and Shahar, 2015) or whether they are currently experiencing positive or negative emotions (see review by Schoeppe et al., 2016). An important aspect, and potential limitation, of self-monitoring or wearing devices such as Fitbits or accelerometers is that it can be reactive: in other words, it acts as an intervention, with participants modifying their consumption on the basis of their increased awareness of their intake or behaviour. Behaviour that is seen as undesirable is likely to decrease while being monitored, whereas desirable behaviour is likely to increase. This may be useful in a clinical context, where the intention of self-monitoring *is* behaviour change, and indeed many recent studies of diary 'apps' are intervention trials and report success of monitoring when compared to a control group who do not monitor. However in a research context the reactivity of such measurement tools may prevent researchers from obtaining reliable baseline measurement of behaviour against which to evaluate the efficacy of an intervention programme. Reliance on self-monitoring data can also create problems clinically: for example, Warren and Hixenbaugh (1998) reviewed evidence that people with diabetes make up their self-monitored blood glucose levels and found that, in some studies, individuals did so in order to present a more positive clinical profile to their medical practitioner (i.e. self-presentation bias/**social desirability bias**). This behaviour could potentially disadvantage treatment efficacy or disease management and outcomes.

While self-monitoring techniques could potentially elicit self-presentation bias, there is evidence that collecting data via *face-to-face interviews* can also elicit such bias. Face-to-face interviews enable researchers to seek more explanation for a person's behaviour by using open-ended questions such as 'Think back to your first under-age drink of alcohol. What would you say motivated it? How did you feel afterwards?' Interviews also facilitate the building of rapport with participants, which may be particularly important if the study requires participants to attend follow-up interviews or complete repeated assessments. Rapport may increase commitment to the study and improve retention rates; however, the interview process, content and style may also influence participants' responses. Some people may simply not report their 'risk behaviour' practices (e.g. illicit drug use, unprotected sexual intercourse) or lack of preventive behaviour practices (e.g. toothbrushing, exercising) in the belief they will be judged to be 'deviant', in poor health, or simply as being careless with their health (e.g. impression management is common: i.e. people monitor and control (actively construct) what they say in order to give particular impressions of themselves (or to achieve certain effects) to particular audiences (Allport (1920) first noted this in the domain of social psychology)).

So how can you tell whether health behaviour data that are collected provide a true representation of behaviour or simply the outcome of self-presentational processes? It is probably best to assume that they are a bit of both, and when reading statistics regarding the prevalence of particular behaviour, stop to consider the methods used in generating the data and ask yourself what biases, if any, may be present.

**social desirability bias**

the tendency to answer questions about oneself or one's behaviour in a way that is thought likely to meet with social (or interviewer) approval

# Unhealthy diet

What and how we eat plays an important role in our long-term health. Heart disease and some forms of cancer have been directly associated with diet. The degree of risk for cancer conferred by diet may be surprising. While many cancer deaths (approximately 30 per cent) are attributed to smoking cigarettes, it is perhaps a lesser-known and discussed fact that 35 per cent of cancer deaths are attributable in part to poor diet. A diet involving significant intake of high-fat foods, high levels of salt and low levels of fibre appears to be particularly implicated (American Cancer Society 2012).

Our dietary intake and behaviour (e.g. snacking, bingeing) may also confer an indirect risk of disease through its effect on weight and obesity. More specifically, some estimates suggest that excess body weight results in: 20 per cent of all cancer deaths (specifically cancers of the breast, colorectal region, oesophageal, endometrial, kidney, pancreatic, thyroid and gallbladder, National Cancer Institute, 2016); over 7 per cent of the global disease burden; about a third of heart disease and stroke; and over 60 per cent of hypertension incidence (WHO, 2020b). Abdominal obesity, that is a high waist to hip ratio ('apple shape') is particularly implicated in heart attack and hypertension, more so than BMI. Waist circumference levels are considered in need of attention where a male's waist exceeds 37 inches (94cm), or a female's waist exceeds 31.5inches (80cm), and where they exceed 40 inches or 34.5 inches for males and females respectively, serious risk to health are likely (BHF, 2020). Problems of overweight and obesity have been rising significantly among children as well as adults, with about a quarter of adults in many Western European countries, and the USA, being obese, and up to 60 per cent being overweight (see later section). Behaviours of poor or overeating and not exercising are central to this 'epidemic'. Yet we eat for many other reasons than health, as discussed below. Furthermore, it has been shown that food desires constitute about a third of our daily desires (Hofmann, Baumeister, Forster and Vohs, 2012), thus attempts to change eating behaviour are not straightforward.

## Fat intake and cholesterol

Excessive fat intake has been found to be implicated in coronary heart disease and heart attacks (Yusuf et al., 2004) and to a lesser extent cancer, particularly colorectal, testicular and breast cancer (Freedman et al., 2008). Cholesterol is a lipid (fat) which is present in our own bodily cells. Normal circulating cholesterol (serum cholesterol) has a purpose in that it is synthesised to produce steroid hormones and is involved in the production of bile necessary for digestion. Serum cholesterol levels can be increased by a fatty diet (and by other factors such as age). While there is not a perfect correlation between dietary cholesterol and serum cholesterol, they are related, which is why cholesterol is of interest to health psychologists concerned with behaviour change!

Fatty foods, particularly foods high in saturated fats (animal products and some vegetable oils), contain cholesterol, a fat-like substance which contains lipoproteins which vary in density. Those known as low-density lipoproteins (LDLs), when circulating in the bloodstream can lead to the formation of plaques in the arteries, and as a result cholesterol carried by LDLs is often called 'bad cholesterol'. LDL appears to be implicated in atherosclerosis (see below), whereas cholesterol carried by high density lipoproteins (HDLs) is called 'good cholesterol', as it appears to increase the processing and removal of LDLs by the liver. Some foods, such as polyunsaturated fats which can be more easily metabolised in the body, or foods such as oily fish which contain Omega-3 fatty acids and which have been found to raise HDL levels, are beneficial to one's health. It is important to keep the actual LDL levels as low as possible, particularly in those with other risk factors for heart disease such as hypertension, family history, or smoking.

If fat molecules, a good store of energy in our bodies, are not metabolised during exercise or activity, then their circulating levels become high, and plaques (fatty layers) are laid down on the artery walls (**atherosclerosis**), causing them to thicken and restrict blood flow to the heart. An often related condition, **arteriosclerosis**, exists when increased blood pressure causes artery walls to lose elasticity and harden, with resulting effects on the ability of the cardiovascular system to adapt to increased blood flow (such as during exercise). These arterial diseases are together referred to as CAD (coronary artery disease) and form a major risk factor for angina pectoris (a painful sign of arterial obstruction restricting oxygen flow) and coronary heart disease (CHD).

Reduced fat intake is a target of health interventions, not solely because of its effects on body weight and, potentially, obesity (see later), but because of the links with CHD. Evidence for this link has come from many studies, including three large prospective studies (MRFIT study of 69,205 men followed over 16 years; CHA study of 11,017 men over 25 years; PG study of 1,266 men over 34 years) where a significant linear relationship between baseline cholesterol level and death from heart disease, stroke, or in fact mortality overall, was reported (Stamler et al., 2000). More recently, a twenty-year observational

atherosclerosis

formation of fatty plaque in the arteries

arteriosclerosis

loss of elasticity and hardening of the arteries

**Photo 3.3** Over-large portion sizes contribute to weigh gain issues!

*Source*: Africa Studio/Shutterstock.

follow-up of over 5,000 Scottish men who did not have vascular disease at study onset but who did have raised cholesterol, found significantly reduced heart disease incidence and all-cause mortality over time in those receiving statin treatment to reduce cholesterol than those who did not receive this (Vallejo-Vaz et al., 2017). While there is some correlational evidence of higher breast cancer death rates in countries where high fat intake is common (e.g. the UK, the Netherlands, the USA) than in countries where dietary fat intake is lower (e.g. Japan, the Philippines), firm causal data is limited, both in terms of breast cancer (e.g. Löf et al. 2007) and prostate cancer risk (Crowe et al., 2008). There is evidence that, at least in Europe, the average fat consumption figure is around 40 per cent, which in terms of grams per day, exceeds the recommended maximum of 30g of saturated fat intake per day for males, 20g for females.

As a result of these and other data, governmental policy documents have been produced in many countries that provide guidelines for healthy eating and dietary targets. Across Europe, aggressive media-based marketing of calorie-dense and high-fat products to children is being monitored and a voluntary code of conduct is in place (European Commission, 2018). More widely, the WHO European Food and Nutrition Action Plan 2015–2020 which was adopted by the WHO Regional Committee for Europe in 2014 addresses food labelling as well as marketing (WHO, 2015).

Ethnicity has been shown to have an effect on fat intake: for example, higher levels of fat intake were found among Bangladeshi males living in the UK than among most other ethnic groups (2012 CHD Statistics). It is worth noting, however, that a systematic review (Cochrane Review) of evidence derived from four randomised controlled trials concluded that fat-restricted diets were no more effective than calorie-restricted diets in terms of long-term weight loss among overweight or obese individuals (Pirozzo et al., 2003), suggesting that dietary change should not focus solely on fat intake but on total intake. A balanced and more Mediterranean-style diet with a high amount of fruit and vegetables, nuts, beans and seeds, with a smattering of fish, meat and egg protein and dairy, is advocated. In relation to older populations, however, there is evidence that low rather than high levels of calorific intake are detrimental to health status and cognitive function, and older men living alone seem particularly vulnerable here (Hughes et al., 2004).

## Salt

High salt (sodium chloride) intake, much of it coming from an increasing overreliance on processed foods, is implicated in those with persistent high blood pressure, i.e. hypertension. The detrimental effects of high salt intake on blood pressure appear to persist even when levels of physical activity, obesity and other health behaviour are controlled and thus educational interventions have attempted to modify intake.

A systematic review and meta-analysis of intervention trials assessed the impact of lowering salt intake in adults who were either normotensive (i.e. 'normal' blood pressure), who had high blood pressure that was not being treated, or who were hypertensive (i.e. had high blood pressure) and being treated using drug therapy (Hooper et al., 2002). Findings were conclusive – while salt reduction resulted in reduced **systolic** and **diastolic blood pressure**, the degree of reduction in blood pressure was not related to the amount of salt reduction i.e. there wasn't a linear association. In addition, the trials had no impact on the number of heart disease-related deaths seen in follow-ups ranging from seven months to seven years, with deaths equally distributed across the intervention and control groups. It seems therefore that interventions targeting salt intake provide only limited health benefits.

In spite of mixed findings, guidelines still exist as to recommended levels of salt intake (see, for example, Action on Salt, 2018). A 'high' salt intake is considered to be in excess of 6g per day for adults, and over 5g per day for children aged 7–14 years (British Medical Association, 2003a), with BHF (2012) data showing a 2010 average intake of 6.3g. While it is perhaps difficult to establish the unique health benefits of a reduced-salt diet when individuals tend to engage in more general dietary change behaviour, the BMA guidelines raise awareness of the need to monitor its intake from early childhood on.

### systolic blood pressure

the maximum pressure of blood on the artery walls, which occurs at the end of the left ventricle output/contraction (measured in relation to *diastolic blood pressure*)

### diastolic blood pressure

the minimum pressure of the blood on the walls of the arteries between heartbeats (measured in relation to *systolic blood pressure*)

## ISSUES

### The changing messages

It is sometimes hard to keep up with health recommendations as new evidence or syntheses of evidence emerge and are typically picked up by the media and summarised in a non-critical manner. Below is one example.

### Are processed and red meat less damaging to health than thought?

The eating of red meats and processed meats, such as bacon and sausage, has in recent years been the focus of guidance on consumption – to try to limit it to three days a week or at least, lower than 90g a day, ideally around 70g per day (World Cancer Research Fund, 2019; US Dept of Health and Human Services, 2015; Public Health England, 2016). Since 2015, processed meat has been considered by the WHO's International Agency on Cancer to be 'carcinogenic' (particularly in relation to bowel cancers), and red meat 'probably carcinogenic'. However the combined findings and conclusions of a) systematic review and meta-analysis of 12 randomised controlled studies which together included over 54,000 individuals, and b) meta-analysis of 17 cohorts of data involving 1.7 million adults, conducted by a team of experts from seven countries was published in the highly respected *Annals of Internal Medicine* in October 2019, reaches a slightly more tempered conclusion (Johnston et al., 2019). These authors conclude that the relationship between eating less red or processed meat and reduced cancer, heart disease or diabetes incidence, was either not statistically significant nor meaningful enough in terms of benefit to population health to warrant the current consumption guidance. The strength of the evidence of benefit to the individual from eating these products less than three times a week was low or very low – although there was a small effect. Their conclusion is a weak recommendation that people continue as they are because the evidence of harmful effect of red or processed meat is uncertain, and the evidence of benefit from their reduced intake limited. The publication of this study stimulated significant media attention – while the WHO and other agencies maintain their recommendations are justifiable, Johnston and collleagues, based on much of the same research evidence, think they do not warrant action.

Media coverage such as this gives the lay public the impression that scientists do not really know what is best for us, or at least, that the story changes as evidence and its examination change, but how do people respond to such accounts?

### WHAT DO YOU THINK?

Do you add salt before you taste? Why? Do you have any idea how much fat, and what type, you consume a day? Where are you on your balance of red or processed meat, fish fruit and veg intake? If you are vegan or vegetarian, did health influence your choice, or other factors concerning our environment?

# Obesity

Even though obesity is not itself a behaviour, it is contributed to, in part, by a combination of poor diet and a lack of exercise, both health behaviours which are the theme of this and the following chapter. Global concerns exist about the increasing prevalence of obesity, which includes a ten-fold increase in obesity among those aged 5–19 years old over the past four decades, leading to a situation where, in 2016 almost 1:5 are either overweight or obese (WHO, 2018, World Health Statistics). The concern arises from evidence of obesity's impact on morbidity (including disability and a range of diseases) and mortality.

## How is obesity defined?

Obesity is generally measured in terms of an individual's body mass index (BMI), which is calculated as a person's weight in kilograms divided by their height in metres squared (weight/height$^2$). An individual is considered to be:

- 'normal weight' if their BMI is between 20 and 24.9 kg/m$^2$;
- mildly obese or 'overweight' (grade 1) if their BMI is between 25 kg/m$^2$ and 29.9 kg/m$^2$;

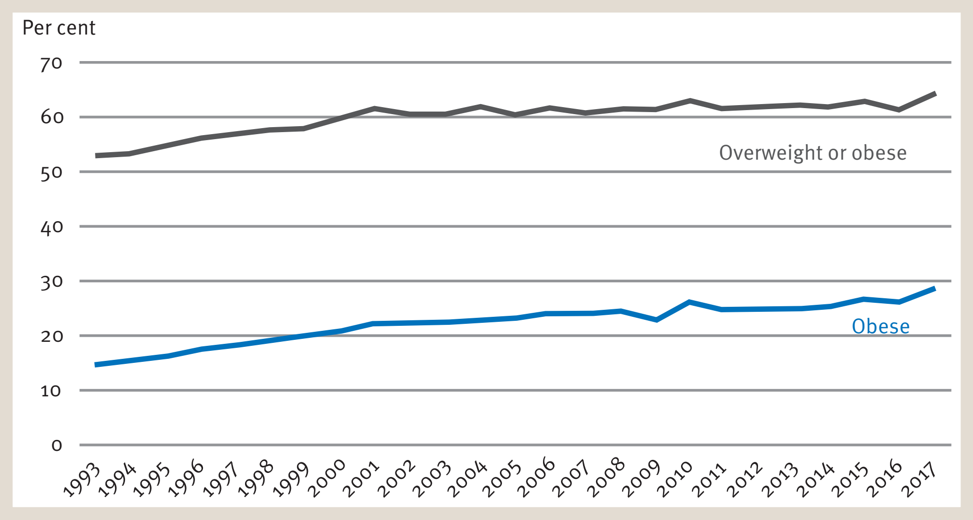

**Figure 3.5** Trend in prevalence of adult overweight and obesity, England

*Source*: NHS England, 2018.

- moderate or clinically obese (grade 2) if their BMI falls between 30 kg/m$^2$ and 39.9 kg/m$^2$;
- severely or morbidly obese (grade 3) if their BMI is 40 kg/m$^2$ or greater.

BMI does not, however, take age, gender or body frame/muscle build into consideration (although BMI cut-offs are based on being 20 per cent above the height–weight chart standards for a person of 'medium' frame), and so the index should only be used as a guide in context with these other factors. As well as considering BMI, as mentioned earlier in this chapter it has become clear that waist circumference, ratio of waist to hip size, and fat deposited around the abdomen (often referred to as being 'apple-shaped') further increase the implications of overweight and obesity for heart attack in both men (Smith et al., 2005) and women (Iribarren et al., 2006), for type 2 diabetes and all-case mortality in women (Hu, 2003) and for some forms of cancer (Williams and Hord, 2005).

## Negative health consequences of obesity

As noted earlier, while being underweight is the largest global cause of mortality, a growing number of people, predominantly in Western or developed countries, experience the opposite problem – obesity. Obesity is a major risk factor in a range of physical illnesses, including, for example, hypertension, heart disease, type 2 diabetes, osteoarthritis, respiratory problems, lower back pain, and some forms of cancer.

The evidence of a linear relationship between the percentage overweight a person is and the relative risk of disease remains mixed. A meta-analysis published in the *Journal of the American Medical Association* (Flegal et al., 2013) concluded from review of 97 study datasets involving over 2.8 million individuals that there was a raised risk (calculating Hazard Ratios (HR) relative to normal weight) of death for grade 2 and grade 3 obesity (combined HR 1.29), but not for those classed as overweight (HR 0.94) or grade 1 obese (HR 0.95). In fact, being 'just overweight' was associated with lower risk of mortality than 'normal' weight. Although based only on BMI and not weight distribution, these were important findings, leading to some academic debate about potential health benefits to being a bit overweight, certainly compared to being underweight. In contrast, the classic longitudinal Framingham Heart Study showed a relationship between obesity and mortality which appears over two to three decades. In their data, being overweight confers slightly more risk than 'normal' weight. In both studies, however, a J-shaped curve exists (see Figure 3.6) which reminds us also of the risk of being underweight.

Apart from physical health problems, obesity is also implicated in psychological ill health including low self-esteem, social isolation and depression (Pereira-Miranda et al., 2017), possibly arising from the experience of stigmatising behaviour (Ogden and Clementi, 2011). Being overweight as a child has been associated with poorer health-related quality of life (Williams et al., 2005) and even earlier mortality (Bjørge et al., 2008).

## Prevalence of obesity

The World Health Organization collation of epidemiological data provides evidence of a three-fold increase in obesity rates in parts of North America, Australasia and China, and within the UK over the past three decades. Among adults in England, 29 per cent were obese in 2017 (4 per cent morbidly so) and the majority (64 per cent) overweight. The slow upward trends from the early 1990s are seen in Figure 3.5 and, while levels have stabilised somewhat since the early 2000s, recent trends have been upwards again. Alarmingly, excess body weight has been identified as the most common child disorder in Europe with the world seeing a ten-fold increase in the number of obese individuals aged 5–19 year olds over the past 40 years (WHO, 2018).

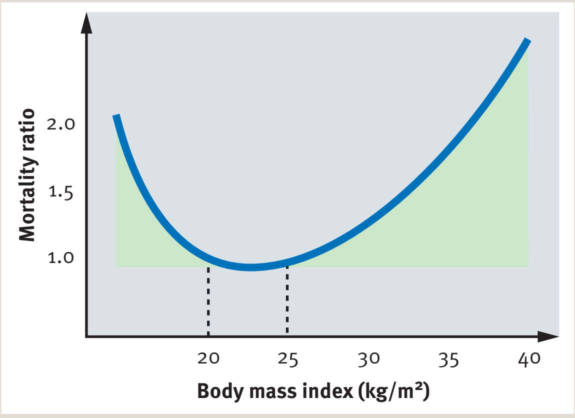

**Figure 3.6** The relationship between body mass index and mortality at 23-year follow-up (Framingham heart study)

*Source*: Wilson et al. (2002).

Obesity affects all age groups; however, in younger populations the particular concerns are about the early implications of obesity for psychological health and psychosocial development, whereas with ageing, as with middle-aged and older adults, the effects on physical health begin to be seen.

Obesity in children and adolescents tends to have a higher prevalence in developed, high-income countries, although the rate at which it is increasing is much quicker in Low and Middle Income Countries. Lower social class has been related to increased obesity for young females, but not for males, and as obese children tend to grow up to be obese adults (Magarey et al., 2003), interventions need to start early. To be successful, interventions need to be multifaceted from policy level interventions to developing understanding around individual level factors. In health psychology we seek to first understand the factors associated with the development of obesity, and to do this consider the range of influences on food choice, consumption patterns and, crucially, overeating behaviour.

Personality plays a role here, for example neuroticism tends to associate with dietary 'pickiness' (fussiness) and **neophobia** (e.g. a study of 451 Scottish children aged between 11 and 15, MacNicol et al., 2003), but most studies have focused on wider factors which fall within social learning theory, e.g. the powerful influence of significant others' behaviour or communications – peers, siblings, parents, the media – or within theories of associative learning where food choice and eating behaviours are associated with the receiving of intrinsic or extrinsic rewards or **reinforcers**, such as the pleasure attached to eating with family and friends, or the perceived stress reduction gained from 'comfort eating'. As well as considering these developmental theories which focus on social learning and modelling, health psychologists have also applied cognitive theories to behaviour change with regards to overeating (see Chapter 5 ☛). It is the case that many normal-weight women wish to weigh less, thus buying in to the idea of 'thinner is better' which is normalised in much media coverage (Wardle and Johnson, 2002). In spite of this, we still face an obesity epidemic and those who are overweight face being judged against this perceived 'ideal'.

**neophobia**

a persistent and chronic fear of anything new (places, events, people, objects).

**reinforcers**

factors that reward or provide a positive response following a particular behaviour or set of behaviours (positive reinforcer); or enable the removal or avoidance of an undesired state or response (negative reinforcer)

Obesity has a strong association with disease, but in considering the influences on it below you will see that it is not solely due to overeating.

## What causes obesity?

A simple explanation of obesity is that it is a condition that results from an energy intake that grossly exceeds the energy output (Pinel, 2003). However, early twin studies and studies of adopted children (who showed weight relationship with biological rather than adoptive mothers, e.g. Price and Gottesman, 1991; Meyer and Stunkard, 1993) proposed some genetic explanations to obesity, which are generally one of three types:

- Obese individuals are born with a greater number of fat cells: evidence of this is limited. For example, the number of fat cells in a person of average weight and in many mildly obese individuals is typically 25–35 million. The number of cells is dramatically increased in a severely obese person, implying the formation of new fat cells.
- Obese individuals inherit lower metabolic rates and thus they burn calories more slowly and therefore they should require fewer calories to survive; however, if they don't know this and eat 'typically' they gain weight. However, research evidence shows that obese people do not consistently have lower metabolic rates than comparable thin persons, thus this common explanation seems unfounded.
- Obese individuals may have deficiencies in a hormone responsible for appetite regulation or control, or lack of control: more potential as a contributing factor.

This last explanation has received attention since the 1950s, when a gene mutation was identified in some laboratory mice that had become highly obese (Coleman, 1979). Subsequent cloning of this mutated gene found that it was only expressed in fat cells and that it encoded a protein hormone called leptin (Zhang et al., 1994). Leptin is produced by fatty (adipose) tissue and is one of several signals to the hypothalamus of the central nervous system that help to regulate weight. Low leptin levels suggest low fat stores which then prompts a signal to the organism to eat, to re-establish fatty stores needed for energy (see Chapter 8 ☛). However, research has not found similar genetic mutation in all obese humans and increasing leptin by means of injection has not consistently reduced eating behaviour or body fat in the obese. The effects of common fat mass and obesity associated gene variants on BMI, weight, waist circumference and body fat (e.g. Frayling et al., 2007) were highlighted by preliminary evidence that genetic susceptibility to obesity could be reduced or even negated by means of vigorous physical activity (Rampersaud et al., 2008).

Another avenue of research has identified that serotonin, a neurotransmitter (see Chapter 8 ☛), is directly involved in producing satiety (the condition where hunger is no longer felt). Early animal experiments investigating the effects on hunger of administering a serotonin **agonist** have had their findings confirmed in humans, where the introduction of serotonin agonists into the body induced satiety, and reduced the frequency and quantity of food intake and body weight (Halford and Blundell, 2000).

Such lines of research hold promise for future intervention; however, it is likely that genetic or physiological explanations are insufficient, particularly when you consider the recent upsurge in obesity in developed countries. Obesity is more likely attributed to an interaction between physiological and environmental factors such as sedentary lifestyle, food marketing and product availability, and individual behaviour patterns. People of all ages increasingly pass their time indoors, and there is evidence that activities such as watching television or computing can even reduce a person's metabolic rate, so that their bodies burn up existing calories more slowly. Lack of physical activity in combination with overeating or eating the wrong food types are associated with obesity, and it is unclear which is the primary causal factor.

People eat for different reasons and it may be that the obese differ from the non-obese in this regard. For many, eating carries positive incentives, such as the intrinsic rewards of taste enjoyment (sensory eating), and extrinsic rewards such as the pleasure of social eating (Pinel et al., 2000). Eating styles exist (van Strien et al., 1986) whereby some people eat when they catch sight of food or food cues (external eating), or simply when their body signals hunger (internal eating); others eat when they are bored, irritated or stressed (emotional eating). There is some evidence that obese people and those who overeat are more external cue responsive and less led by internal hunger cues, and perhaps show more emotional eating (Snoek et al., 2007; van Strien et al., 2007; O'Connor et al., 2008). When eating when stressed, it seems that it is not only the amount of food that increases, but also the type of food selected, often that with high sugar or fat content (Oliver et al., 2000), and furthermore that the type of eating behaviour may differ depending on the nature of the stressor (O'Connor et al., 2008).

Effective interventions which aim to make what has been described as our 'obesogenic' environments (Hill and Peters, 1998) and behaviour more healthy need therefore to address a complexity of factors. Similarly, interventions to increase physical activity, the other major contributor to reduced obesity, are also high on the public health agenda (see Chapters 4, 6 and 7 ☛).

agonist

a drug that simulates the effects of neurotransmitters, such as the serotonin agonist fluoxetine, which induces satiety (reduces hunger)

## WHAT DO YOU THINK?

What style of eating do you have? Are you likely to eat when something looks or smells good even if you have recently eaten and don't actually feel hungry? ('external/sensory eating') Are you easily swayed by others simply eating in front of you? ('external eating') Can you exercise restraint over what and when you eat? For example, if you think you have eaten more than usual over the weekend, do you try to eat less the next day? ('restraint eating'). What about your mood: does that make a difference to when and what you eat? Some people eat less when depressed; others eat more and seek out certain food types – usually sweet or fatty foods. If you're angry, frustrated or impatient, do you snack or nibble more? ('emotional eating').

Styles of eating reported by those with obesity have been 'matched' to different obesity treatments. If you are interested in reading further about this, use the references above and also Google the DEBQ (the Dutch Eating Behaviours Questionnaire, van Strien et al., 1986), a screening tool used in many studies of eating styles and which has been shown to have good construct validity and internal reliability (e.g. Domoff, 2015).

## A final thought on obesity

A word of caution: we as individuals, and as a society, must be careful not to over-focus on the weight of individual children – while obesity is on the increase, so too is extreme dietary behaviour and eating disorders; several studies point to body dissatisfaction among children and adolescents, particularly females (e.g. Schur et al., 2000; O'Connor et al., 2008) which can lead to dietary restraint with potential adverse physical and psychological consequences, including eating disorders (e.g. Stice et al., 2002).

## A final thought on risk factors

Health risk behaviours often co-occur in clusters as shown in an analysis of risk factors for non-communicable diseases (e.g. cancer, heart disease) among a UK representative sample of 3,293 adults (e.g. Birch, Petty, Hooper et al., 2018, see Figure 3.7). In this study over 77 per cent of the sample engaged in at least one health risk factor suggesting that any intervention needs to consider the different influences on and motives underpinning each behaviour (see also Chapter 4 and Chapter 5 ☛).

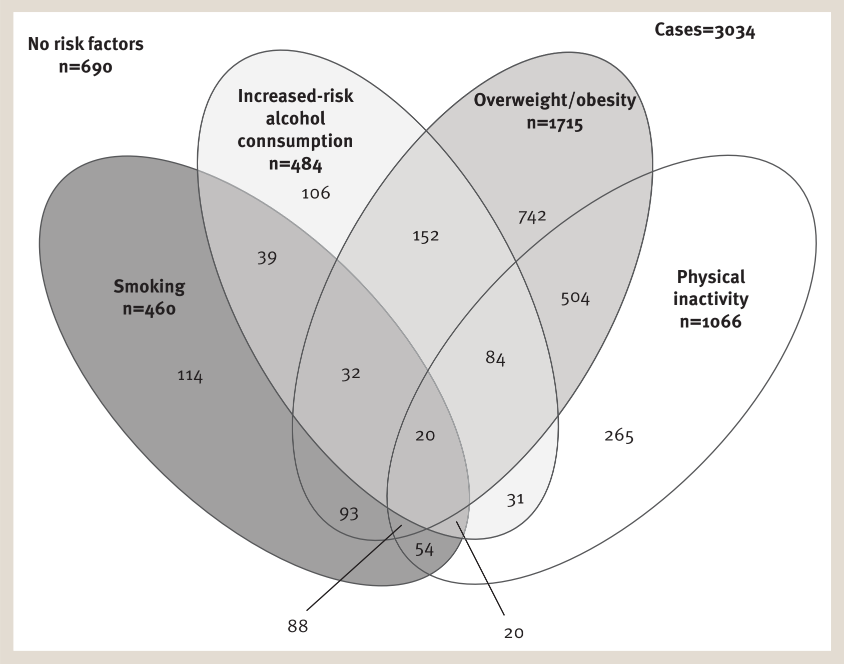

**Figure 3.7** Clusters of risk factors

*Source*: Birch et al, 2018.

## SUMMARY

This chapter has defined health behaviour as those behaviours associated with health status, whether or not they are performed with the explicit goal of health protection, promotion or maintenance in mind. The behaviours addressed in this chapter are sometimes referred to as 'behavioural pathogens' or health-risk behaviour and include smoking, heavy consumption of alcohol, unprotected sexual behaviour and an unhealthy diet. 'Behavioural immunogens' or health-enhancing behaviours, such as exercise, a balanced diet, health screening and immunisation behaviours, are discussed in the next chapter.

This chapter has described behaviours with clear associations with prevalent illnesses, and as such they account for a vast amount of research enquiry within health psychology. A significant body of work has addressed the complexity of social, emotional and cognitive factors that contribute to the uptake and maintenance of health-damaging behaviour, and a range of theories and models of health behaviour which have been developed and tested within health psychology are described in Chapter 5 ☛.

We also in this chapter bring to the reader's attention some of the challenges to effective measurement of health behaviours. As elsewhere in this text, we encourage readers to stop and think about the data on which a lot of the evidence we review is built, and to do this they may need some further individual reading.

## Further reading

Ferrer, R.A. and Mendes, W.B. (2018). Emotion, health decision making, and health behaviour. *Psychology & Health*, 33:1, 1–16, DOI: 10.1080/08870446.2017.1385787

In a detailed editorial introducing an excellent special issue, Ferrer and Mendes describe the emotional context in which decisions are taken around health or risky behaviour which, like personality, is often given less research consideration than factors such as individual beliefs and expectancies (see Chapter 5 (☛). This Special Issue warrants a read, and many of the articles contained therein are cited in this textbook.

West, R. (2006). *Theory of Addiction*. Oxford, Blackwell.

Reading this will give the interested reader an excellent grasp of both psychological and social models of addiction.

*The World Health Statistics 2018: Monitoring Health for the SDGs* (Sustainable Development Goals), Geneva: World Health Organization.

This report brings together global data from world member states relevant to the achievement of the ambitious 'sustainable development goals' – for our purposes those related to the health and wellbeing goal concern statistical trends in infectious disease, non-communicable disease and obesity.

*The World Drugs Report 2019*, United Nations Office on Drugs and Crime, Vienna.

This report comes in five parts, with Part 2 most relevant to our needs as it provides useful and up-to-date statistics regarding trends and consequences of the use of illicit substances. (United Nations publication, Sales No. E.19.XI.8).

For information regarding worldwide HIV and AIDS figures, campaigns and news: http://www.avert.org/

# Chapter 4

# Health-protective behaviour

## Learning outcomes

**By the end of this chapter, you should have an understanding of:**

- **the behaviour found to have health-enhancing or health-protective effects**
- **the relevance of adherence to medicine and treatments, healthy diet, exercise, screening and immunisation to health across the lifespan**
- **the range and complexity of influences upon the uptake and maintenance of health-enhancing behaviour**

## Is getting outdoors and into the natural environment good for our health?

In this chapter we will describe evidence as to the benefits of physical activity to our physical health as well as to our emotional wellbeing. In this opener we raise the question of whether we as a society, or as health psychologists, should focus mainly on physical health gains of regular moderate to intense physical activity, or whether we need also address the benefits of more leisurely and reflective activity to our wellbeing. For example the wellbeing benefits of engaging with our natural environment, our green and blue spaces (e.g. forests, fields, coast and seas) are increasingly being researched and evidence of their benefits are growing.

Having access to, and making use of greenspace in one's neighbourhood has consistently been associated with reduced stress and anxiety and improved emotional wellbeing. One thing the recent COVID-19 pandemic has highlighted is how people in both urban and rural settings place value on getting outdoors, whether to small enclosed gardens or to large green spaces. The Japanese have led the way in examining the effects of green space on wellbeing with a tradition known as *Shinrin-Yoku*, or forest-bathing, with beneficial effects of woodland walking or simply sitting and taking in sensory experience of calming sounds and smells and the visual distractions offered by nature.

Such evidence has contributed to policies developed to connect people with the environment in order to improve health and wellbeing, for example, the UK government's 25-year environment plan (UK Government, 2018). That nature benefits our wellbeing is not a new idea; however, it may be that the next decade will see us better address this natural medicine, while we consider the challenges climate change, pandemics and potential lockdowns present to our behaviour and lifestyle. It must also be noted that huge social inequalities exist, not only in access to formal activity spaces such as gyms or leisure centres (due to cost), but also in access to green space (due to residential location, transport systems etc.). Throughout this textbook we endeavour to highlight the impact such inequalities can have on health, behaviour and wellbeing.

## Chapter outline

Behaviour is linked to health and, as shown in Chapter 3 ☛, many of our behaviours have negative effects on our health; however, thankfully, other behaviours can benefit our health, and even protect against illness. These are sometimes called 'behavioural immunogens', and in this chapter we present an overview of the evidence surrounding a range of such behaviours, including medication or treatment adherence, healthy diet, exercise behaviour, health screening and immunisation. The scientific evidence pertaining to the health benefits of these behaviours is considered, and some national guidelines in relation to their practice will be provided. A broad array of influences on the uptake or maintenance of specific health-protective or enhancing behaviour is introduced to the reader here in order to provide a foundation for Chapter 5 ☛, where key psychosocial theories of health behaviour and health behaviour change are explored fully.

In a society where chronic disease is prevalent and where the population is ageing, it is increasingly important to take positive steps towards healthy living and healthy ageing. While media coverage and public health campaigns work towards increasing awareness of the beneficial effects of some behaviours on health, it is important to remember that people do not always behave as they do to protect their health or to reduce their risk of illness; for example, they exercise for fun or for social reasons. As health psychologists, it is important to develop an understanding not only of the consequences of certain behaviour for health but also of the many psychosocial factors that influence its performance. Individual behaviour can both undermine (see Chapter 3 ☛) and act to protect and maintain health (this chapter). The dominant psychosocial theories applied and tested in this regard are described in Chapter 5 ☛, and the manner in which such behaviours provide targets for educational and health promotion endeavours worldwide are discussed in Chapters 6 and 7 ☛.

We start the chapter with a look at adherence behaviour, focusing on medication and treatment adherence; however, the principles are relevant also to adhering to behaviours addressed in the preceding chapter (e.g. smoking cessation) or elsewhere in this chapter (e.g. healthy eating, exercise).

## Adherence behaviour

### Definition and measurement

Depending on whether you are reading from medical literature, pharmacological literature or psychological literature, you will come across the terms 'compliance', 'concordance' or 'adherence' being used to refer to the act of acquiring prescriptions and taking medicines appropriately, or carrying out other illness self-management behaviours such as rehabilitation exercises, as advised by a healthcare professional. Although often used interchangeably, these terms are considered to suggest a different relationship between a patient and a healthcare professional, as we illustrate with the brief definitions below:

- *Compliance*: most often used in medical literature, this term suggests patient medicine taking behaviour which conforms with 'doctor's orders', and thus non-compliance may be interpreted as wilful or even incompetent. The term 'patient compliance' was introduced in 1975 as an official Medical Subject Heading (MeSH term), used when conducting systematic literature reviews, something you may need to do at some point!
- *Adherence*: this term suggests that a person sticks to, or cooperates with, advice about medication (or lifestyle changes, behaviours) (NICE, 2009a) in a more collaborative practitioner–patient relationship (di Matteo et al., 2012; Vrijens et al., 2012). Adherence is viewed as a behaviour, a process influenced by individual and environmental factors including healthcare practices and system influences. 'Medication adherence' became a MeSH term only in 2009 (for electronic searches in systematic reviewing), and is the term most often used in health psychology and behavioural medicine although the newer term of concordance below overlaps significantly.
- *Concordance*: introduced by the Royal Pharmaceutical Society of Great Britain in 1995, this term is more often used in pharmacological or therapeutic literature to describe a jointly determined agreement between physician and patient as to what is the appropriate treatment, following the patient having been fully informed of the costs and benefits of adhering to their particular treatment. It does not explicitly describe adherence behaviour, but more the conditions in which to encourage it (see also Chapter 10 ☛ for a discussion of shared decision-making).

The World Health Organization's own definitions of adherence have changed from being 'the extent to which the patient's behaviour coincides with the clinical prescription' (suggesting accidental match rather than agreed behaviour) to one which emphasises partnership in terms of adherence being 'the extent to which the patient's behaviour corresponds with agreed recommendation from a healthcare provider' (WHO, 2009b).

Non-adherence behaviour, i.e. failing to follow recommended treatment or advice, can vary in extent, for example, from not filing a prescription in the first place (estimated occurrence in between 14–21 per cent), to skipping an occasional dose, through to skipping many doses or not taking at all. The various forms of non-adherence carry differing consequences, and as we describe below may occur for different reasons.

Thresholds, in terms of the amount of medicine taken, or behaviours performed appropriately in order *not* to be categorised as non-adherent, range from 70–100 per cent depending on the disease and the treatment concerned (as discussed below). This makes study comparison difficult. The consensus, however, is that a clinically relevant cut-off should be used wherever possible (Vitolins et al., 2000). In other words, if 60 per cent of a drug is needed to be taken daily for it to be effective, then any less than that should be defined as non-adherence. For example, Sherr et al., (2010) report that although as many as 57 per cent of their sample of HIV-infected adults in receipt of a prescription for HAART (Highly Active Antiretroviral Therapy, also known as ART) had taken a tablet at the wrong time in the previous week, it was the 10 per cent who reported having missed two or more dosages within the past week who risked a worse disease prognosis as a result. Thus in terms of setting clinically meaningful thresholds for defining non-adherence, in this instance adherence to HAART (once per day regimen) requires 70 per cent or better (i.e. 5 doses of 7 need be taken for optimal effect).

Why do definitions matter? They matter because if we are to measure the nature and extent of adherence or non-adherence, we have to know what it is we are assessing. Conceptual overlap and conceptual confusion are not helpful if one is to synthesise a literature, something some of you may discover if you carry out research in this domain. One attempt to assist in this was the work of the ABC (Ascertaining Barriers to Compliance) group, a multinational group of researchers from Poland, the UK, Belgium and Switzerland, where a systematic review of terminology as used in papers published prior to April 2009 led to the proposal of a new taxonomy of medication therapy management, where 'medication adherence' is the preferred term and, within that, initiation, implementation (the extent to which the patients actual dosing corresponds to the prescribed regimen) and discontinuation is specified (Vrijens et al., 2012, see Figure 4.1). The work of this EU-funded group included a 12-country survey of health psychology and health economic predictors of adherence behaviour in people with hypertension

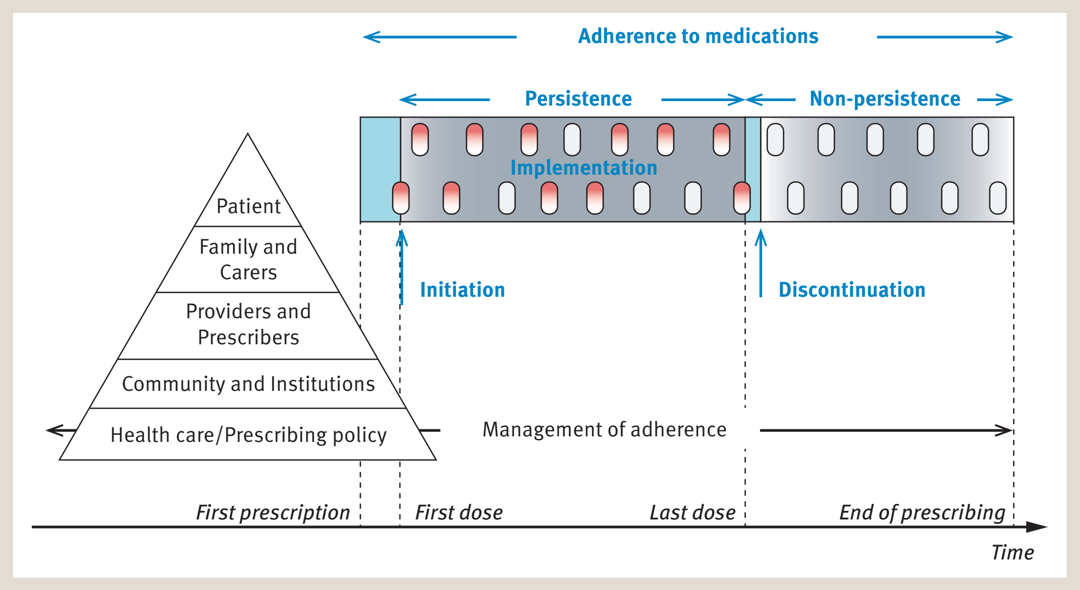

**Figure 4.1** Taxonomy of adherence

*Source*: Vrijens et al. (2012).

(see Chapter 5 ☛, Holmes et al., 2014; Morrison et al., 2015, and www.abcproject.eu).

In addition to the challenges of shared definitions described above, adherence researchers also face challenges when it comes to measuring adherence. Statistics are often derived from patient self-report that, while more reliable than asking the health professional involved in their care (who generally overestimate adherence), may be subject to recall and reporting bias. Some studies therefore gather data on adherence using mixed methods, combining self- and other-report, with biological measurements (e.g. urine or blood testing), or pill counts, including using electronic monitoring systems (MEMS, where counters are in the lids of pill bottles to record timing of openings). All methods have their limitations and, as it stands, no gold standard measure exists, although MEMS is often described as this (diMatteo, 2004a). A meta-analysis of 11 studies (total of 1,684 participants), where both self-reported methods as well as electronic MEMS systems were used to record adherence, reassuringly found an overall moderate correlation between the two methods (0.46). Seven of the eleven studies were conducted with those receiving treatment for HIV, and within a separate meta-analysis of those studies the correlation was just slightly stronger (0.51) (Shi et al., 2010). Interestingly, there is also evidence that the method of dispensing medicines can itself affect adherence. For example, in a randomised controlled trial conducted among adults with type 2 diabetes (Sutton et al., 2014) participants provided with a MEMS device which recorded the date and time of each opening of the container were modestly more adherent than those whose oral medication was contained in standard paper packaging.

So, how well do people adhere and does it matter if they do?

## Do people adhere?

Hippocrates (*c.* 400 BC) was the first documented recorder of the finding that patients did not take medicines as prescribed, and that they even complained when they didn't seem to get better! Currently national and global estimates are that about a half of all medicines prescribed for chronic conditions are not taken as prescribed (e.g. OECD/EU, 2018), and over all conditions, acute and chronic, about 25 per cent are non-adherent. However, adherence rates vary depending on many factors including the condition itself. A meta-analysis of data from 569 different study samples found some similarities across conditions; for example, adherence among those with cardiovascular disease averaged at

77 per cent, similar to the taking of essential immunosuppressant drugs among adult organ transplant patients (Dew et al., 2007). However, variation seen across many conditions has been attributed in part to treatment complexity (number, amount, type of administration, timing of medicines, etc.) and individual beliefs about, as well as actual, illness severity, and many other factors as described below.

## The costs of non-adherence

Patients themselves recognise the costs of non-adherence. For example, Annema et al. (2009) report that one-third of patients with heart failure described improvement in their adherence to their treatment regimes as the most important factor preventing hospital readmission. Few patients, however, probably realise the actual financial costs of non-adherence. For example, across Europe poor adherence to prescribed medication is thought to contribute to about 200,000 premature deaths each year and cost approximately €125 billion annually in terms of excess hospitalisations, emergency care, or outpatient appointments. Within the UK NHS alone, this figure has been estimated at approximately £600 million per year. This includes an estimated cost of £300 million on medicines wastage, e.g. unused and unwanted prescription medicines stored in individuals' homes, returned to pharmacies, or disposed of within care homes (York Health Economics Consortium and University of London, 2010; OECD/EU, 2018). It is hard to ascertain what further costs can be attached to non-adherence to recommended behaviour change following illness events, such as dietary change or smoking cessation following a heart attack, but they are likely to add further to this huge figure.

## Why do people not adhere to medical recommendations and treatments?

The reasons for non-adherence are many and varied, but systematic reviews have identified that factors fall into the following groupings (Sabaté, 2003; Kardas, Lewek and Matyjazsczyck, 2013):

- *Individual-related factors*: e.g. culture, personality, knowledge, personal, familial and cultural beliefs, attitudes towards illness and medicines including lack of trust in doctors or healthcare, self-efficacy beliefs (see Chapter 5 ☛) and low levels of social support/low family cohesion.
- *Condition-related factors*: e.g. symptom type, perceived severity (*not* actual severity, diMatteo et al., 2007), presence or absence of pain, presence of comorbidities, better prognosis.
- *Treatment-related factors*: e.g. the complexity (number, type, timing, frequency and duration) of dosage of medications, presence and extent of side-effects, expense.
- *Socio-economic factors*: low educational level, unemployment, costs of treatment (relates also to socio-economic equalities associated with ethnicity), access to dispensing pharmacy, social isolation, low acculturation.
- *System-related factors*: poor communications with healthcare provider regarding medicines, necessity or function, presence of traditional healing beliefs and systems.

For most people non-adherence will be influenced by a mixture of the above: not all non-adherence will be intentional, and not all non-adherence carries the same risks to health. Research tends to distinguish between intentional non-adherence (e.g. 'I stopped taking my pills as they made me feel sick/are too expensive') and unintentional non-adherence (e.g. 'Sometimes I forget to take a dose if I'm busy' as they are likely to have different predictors (Holmes et al., 2014; Morrison et al., 2015).

One useful measure, the Pain Medication Attitudes Questionnaire (McCracken et al., 2006) assesses concerns and beliefs about pain medication across seven concern subscales:

- Concerns about addiction
- Concerns about withdrawal (negative effects if stop using)
- Concerns about side effects
- Mistrust in doctors
- Perceived need for medication
- Concerns over scrutiny from others
- Worries about tolerance.

Influences on (non-) adherence can be considered as going from the micro level, which includes personality (for example, the association between neuroticism and medication non-adherence in older adults, Jerant et al., 2011), to the macro and meso level, such as culture and social systems. While a significant body of research has identified individual characteristics such as social class (Chapters 2 and 10 ☛), and psychological characteristics such as attitudes and expectancies (Chapter 5 ☛), which are associated with non-adherence, few studies have explored the wider 'structural' influences on adherence behaviour, such as social, cultural, economic and political influences.

### The need to consider sociocultural context

Few studies have explored non-adherence in non-Western populations. Illustrating the importance of structural and system level influences, Kagee and Deport (2010) describe barriers to adherence to Antiretroviral Therapy (ART) (a treatment which can significantly reduce AIDS deaths, but which needs to be taken fully and properly to be effective). Both micro- (the person's immediate environment, family, school, work), macro- (the cultural and political context) and meso- (social institutions such as healthcare systems, transport systems, local economy) system influences were identified in qualitative interviews with ten patient advocates, appointed to provide support, mentoring and counselling to patients with HIV in South Africa. This study highlights influences with specific relevance to the African cultural context: for example, poverty-related hunger was considered to increase the side effects of ART if it were taken on an empty stomach which then reduced the patient's willingness to take their medicines; the distance many needed to walk to clinics to receive treatments when feeling too fatigued to move was a further barrier; and taking medication was, by some, considered as reflecting a lack of faith in God's ability to heal, or in ancestral powers. These perceived barriers would be more unlikely if the sample had been recruited in a Western culture. The religious and spirituality factor identified adds a further dimension that interventions would need to address sensitively, possibly, the authors suggest, by building spiritual beliefs into adherence counselling. Finally, several of the identified barriers emerge in most HIV-related studies regardless of culture, such as waiting times at clinics, perceived stigma limiting the disclosure of diagnosis, health literacy and the challenge of understanding complex medical regimes, and other confounds such as drug injecting behaviour. Such findings highlight a need for greater education and more accessible, better staffed, and confidential services – structural and societal factors that may not fall within health psychology's remit per se, but due to their potential impact upon patient experience are factors we need to consider. Micro-cultural variations exist also: for example, in a UK (Birmingham) study of adherence to oral pharmacotherapy for conditions including diabetes, those of Caribbean, African or 'Other Black' ethnicity, and also those whose first language was Urdu or Bengali, were the least adherent. The Birmingham primary care population constitutes 70 per cent from BME (Black and Minority Ethnic) groups (the highest in England) and so one would have hoped services were better equipped to support the adherence of the sub-populations therein (Aston Medical Adherence Study (AMAS), 2012)

The contribution of both macro (societal) and micro (individual) influences on behaviour continues below in our exploration of influences on other health behaviours (Chapter 5 ☛). Chapter 10 ☛ describes some of the efforts made to maximise adherence and, given evidence of generally moderate impact (see Haynes et al., 2008 for a Cochrane review and meta-analysis), some of the challenges faced.

## Healthy diet

As described in the previous chapter, what we eat plays an important role in our long-term health and illness status, with diet having both direct and indirect links with illness. For example, fat intake is directly linked to various forms of heart disease by a range of physiological mechanisms, and indirectly related to disease by virtue of its effects on weight control and, in particular, obesity. The WHO report that the world has seen a more than ten-fold increase in the number of obese children and adolescents aged 5–19 years in the past four decades, with an estimated 340 million being either overweight or obese in 2016 (WHO, 2020b). Across the UK, 22 per cent of primary school starters (aged 4–5 years) and 34.3 per cent of those aged 10–11 years fell into those categories (Public

Health England, 2020) as did 64 per cent of adults (NHS Digital, 2018). In accordance with such figures, the World Health Organization (WHO, 2019), in its Thirteenth General Programme of Work 2019–2023, recognises that evidence-based interventions that target risk factors such as nutrition early in the life course, will increase 'human capital' at that time and in the future, i.e. healthy behavioural habits set in childhood tend to carry forward into adulthood. Similarly, obesity in childhood is associated with an increased risk of adult obesity and associated diseases such as diabetes and CHD that lead to disability and even premature death (WHO, 2018). In terms of nutrition (a partial explanation of obesity) a low intake of fruit and vegetables is responsible for over 3 million deaths a year worldwide, from cancer or cardiovascular disease, and, furthermore, one-third of cancer deaths are attributable, in part, to poor diet, particularly high intake of fats, salt and sugar and low levels of fibre (American Cancer Society, 2012) (see also Chapter 3 ☛). Only 18 per cent of children eat the recommended 5+ portions of fruit and vegetables per day (NHS Digital, 2020).

Given these reports, it is no surprise that government bodies, health ministers and medical authorities produce guidelines on how to eat healthily, and that health researchers are working towards identifying factors that facilitate the adoption of these guidelines in our daily lives.

## The health benefits of fruit and vegetable consumption

Fruit and vegetables contain, among other things, vitamins, folic acid, antioxidants (for example, beta carotene, or lycopene in the red pigment of tomatoes, polyphenols in red grapes) and fibre, all of which are essential to a healthy body. They may also offer protection against chronic and life-threatening disease. For example, a large-scale review and meta-analysis of data from prospective studies found limited evidence of benefits of consumption for cancer risk; however, all-cause mortality and risk of cardiovascular disease was significantly reduced by higher fruit and vegetable intake (examining data from between 450,000 to over half a million study participants!) (Wang et al., 2014). A dose–response relationship was noted whereby the reduced risk of cardiovascular mortality increased per additional portion of fruit and vegetable intake, up to a threshold of around five portions per day, after which no further reduced risk was observed. This finding is very important, given recent debates regarding five, seven or even ten portions of fruit and vegetables a day.

With regards to cancer risk, however, earlier reports of associations between fruit and vegetable intake and risk of some forms of cancer exist (e.g. Marmot et al., 2007). Similarly a nationally representative study using the Health Survey for England dataset of over 65,000 adults aged over 35 (Oyebode et al., 2013) reports a reduced cancer risk, as well as reduced all-cause and cardiovascular disease risk, with benefits gained from fruit and vegetable intake up to seven portions a day. This study correctly controls for many risk factors such as age, alcohol consumption and levels of physical activity, but not, sadly, for smoking, a known risk for such mortality. It is also a nationally representative sample unlike many other databases e.g. EPIC (see below).

It may also be that national variation exists depending on other lifestyle factors. For example, where fruit and vegetable intake is *combined* with a Mediterranean diet (e.g. low fat, fresh produce, more fish, less meat), there may be a stronger association between fruit and vegetable consumption and reduced disease risk. This was found within the Greek cohort of the EPIC study (Trichopoulou et al., 2009), whereas the pooled data across ten countries showed a weak relationship (Wang et al., 2014). However the sample in the EPIC study heavily relied on those accessing healthcare services or systems and who are perhaps more likely to be health conscious.

Further evidence of the beneficial effects of high fruit and vegetable intake comes from a large **meta-analysis** of data involving 124,706 men and women where vegetarians had significantly lower cancer incidence and significantly lower rates of **ischaemic heart disease** mortality (Huang et al., 2012) than non-vegetarians.

**meta-analysis**

a review and re-analysis of pre-existing quantitative datasets that combine the analysis so as to provide large samples and high statistical power from which to draw reliable conclusions about specific effects

**ischaemic heart disease**

a heart disease caused by a restriction of blood flow to the heart

However, vegetarians also reported lower rates of smoking and lower levels of alcohol consumption than non-vegetarians, risk behaviours which were not always controlled for in the analyses. It is crucial that these and other health risk behaviours are considered when comparing sub-populations as important sample differences may exist which may account for some of the health differences claimed. Such results should not lead one to conclude that vegetarianism is protective against such diseases (Katz and Meller, 2014).

Overall, however, the research evidence is fairly consistent in finding positive health benefits of fruit and vegetable intake (e.g. Katz and Meller, 2014). In gaining understanding of why such effects are found, research has pointed to the presence of **antioxidant** compounds known as ‘polyphenols’, such as the flavonoids (specifically flavonol), and in the case of tomatoes, lycopene (more being released when cooked than when eaten raw). Other methods of effect have also been examined by researchers in human biology, biochemistry and physiology and some answers are being found within the basic building blocks of life – our DNA! A well-conducted survey of 4,676 healthy female nurses followed over a ten-year period. found that healthy and well-rounded Mediterranean-style diets high in fresh fruit and vegetables, fish and white meat, for example, are associated with longer and healthier telomeres (Crous-Bou et al., 2014). **Telomeres** are little caps on the end of our chromosomes which store our DNA and when they shorten and weaken this is thought to be involved in a range of disease, and indeed general ageing. Diet may play a role in shortening and weakening them, with beneficial effects attributed to antioxidant and anti-inflammatory effects of Mediterranean type diets (e.g. Vidacek et al., 2018).

**antioxidants**

oxidation of low-density lipoprotein (LDL or ‘bad’) cholesterol has been shown to be important in the development of fatty deposits in the arteries; antioxidants are chemical properties (polyphenols) of some substances (e.g. red wine) thought to inhibit the process of oxidation

**telomeres**

a compound found at the end of chromosomes that protect against DNA loss during cell replication and which need to be an optimal length to prevent this; short telomeres have been implicated in ageing

This relatively new body of work has opened up exciting research exploring the processes by which our behaviour may impact our health. In Chapter 3 ☛, we looked at a physiological route through which smoking is linked to heart disease risk, i.e. via hardening of the arteries, but we can now also consider nutrition and ‘gene health’ (see also Chapter 11 ☛ in relation to stress and gene health). Scientific advances in genetic physiology are beyond the scope of detailed exploration in this psychology text; however, interested readers can follow this up in their own reading.

In relation to reduced coronary heart disease risk, the effects of a healthy diet high in fruit and vegetable intake may also be indirect via effects on weight (see Chapter 3 ☛ for discussion of obesity) and there remains a need for further controlled nutritional trials to ascertain what and how any benefits are achieved (Dauchet et al., 2009; Katz and Meller, 2014).

## Why do people not eat sufficient fruit and vegetables?

Much of the research carried out with regards to healthy eating focuses on young people’s food choices and eating behaviours, and, while this makes sense in relation to the growing prevalence of obesity (see Chapter 3 ☛) and in light of the fact that health behaviours set down in childhood can contribute towards adult health state, our society is an increasingly ageing one and therefore a greater focus on ‘healthy ageing’ is also required. A loss of appetite and reduced energy are often associated with growing older, but are not inevitable consequences and may reflect social factors (such as experiencing a loss of interest in food caused by eating alone), physical factors (access to shops, physical mobility) or psychological factors such as depression. It may be that older males, when widowed, face a particular challenge when having to shop and cook for themselves, as among much of the current older population such roles have commonly been adopted by women. Hughes et al. (2004) carried out a questionnaire and interview study of 39 older men and found that only five (13 per cent) consumed five portions of fruit and vegetables a day, that 64 per cent consumed less energy than appropriate even when controlling for BMI, activity and age, and most had lower intake of essential nutrients than they should. Interestingly, this study relates food intake to the individual's cooking skills with perhaps unexpected findings. Those with good cooking skills reported higher vegetable intake but lower energy/calorie intake, whereas men with poorer cooking skills ate less vegetables but tended to eat more calorie-dense foods which, even if in line with calorie intake guidelines, is not necessarily a good thing as energy-dense foods are not always nutritious. The implication of such findings is that interventions should be quite practical, tying up cooking skills with both appropriately calorific and nutritious food.

In spite of growing public awareness of the link between eating and health, fruit and vegetables tend not to be the food of choice of many young people. For example, the National Diet and Nutrition Survey (Food Standards Agency, 2000) found that the foods most frequently consumed by British young people (aged 4 to 18 years) were white bread, savoury snacks (e.g. crisps), biscuits, potatoes and confectionery, although an encouraging trend was seen in terms of increased fruit intake compared to previous years. Although the average vitamin intake was not deficient, intake of some minerals was low. More recently this repeated survey has reported an encouraging decline in consumption of sugary soft drinks, but all age groups (from aged 1.5 years to over 75 years) failed to meet government recommendations for either fibre intake or for saturated fat intake (Public Health England & Food Standards Agency, 2020).

Food choice can in part be understood by factors other than health recommendations. For example, a survey of British young people (Haste, 2004) found that children gave 'It tastes good' (67 per cent) and 'It fills me up' (43 per cent) as the top two reasons for their favourite food choice, above 'Because it is healthy' (22 per cent) and 'It gives me energy' (17 per cent). Enjoyment is important – if a person enjoys what they are doing, they are more likely to repeat that activity. This applies to healthy eating

**IN THE SPOTLIGHT**

### Just how much fruit and veg is enough?!

In 1990 the WHO advised an intake of 400 grams of fruit and vegetables a day, with one portion equating to about 80 grams. This led to the UK launching its '5-a-day' campaign in 2003, which has also been embraced in other European countries, including France and Germany. Data from the Health Survey for England 2018 (HSE, 2018) found that only 18 per cent of children aged 5 to 15 were found to be eating at least five portions per day. While this is higher than in earlier surveys, it still reflects a small proportion of children. There is also substantial evidence that the majority of adults are also not following these recommendations, with the above survey finding only 28 per cent to be eating 5 portions a day (the average was 3.7 portions) with this being lower among males, and among young adults aged 16 to 24 years.

Elsewhere the campaign has differed, with higher guidelines existing for example in Australia where the 'GO for 2 + 5' campaign has since 2005 provided recommendations for two servings of fruit (a serving being judged as 150 grams which is equivalent to your average apple) PLUS 5 servings of vegetables (with a serving being weighed in as 75 grams, about half a cup full of vegetables). It is notable that the Australian guidelines equate to 675 grams of daily intake, which in UK terms would be 8.5 portions, significantly more than the five portions currently recommended. Higher guidelines do not necessarily make for better consumption. The 2017–18 National Health Survey in Australia revealed that 49 per cent of adults aged over 15 years were failing to meet the recommended intake for fruit, but even more worryingly, 92 per cent failed to meet the recommended vegetable intake (Australian Bureau of Statistics, 2018).

In the USA, the '5 - a - day' approach was dropped in favour of a campaign simply promoting eating 'more' of both. Do health recommendations need to be precise and consistent in order to be taken seriously? In an article in the *Daily Mail* (2 April 2014), asking whether you should be eating seven a day, two views of the new proposals were presented. The first is from a 'food writer' who argues that if we fail to meet the five portions currently recommended, there is no advantage in

*(continued)*

simply upping that to seven without seriously addressing the barriers to behaviour change (costs, availability etc. and personal barriers) (see Chapter 5 ☛). The second comment comes from a 'cancer expert', a doctor who fully supports the need for higher intakes in the battle against increased cancer and heart disease risk, and who in fact advocates cramming in as much fruit and vegetables as we can.

So, what do you do? As students being trained in reviewing an evidence base, I would advise behaviour based on current knowledge. As reviewed in this chapter, two large studies, one multinational (Wang et al., 2014), one UK based (Oyebode et al., 2013) support 5–7 portions a day as being sufficient to accrue health benefits over time, but with the caveat that other risk factors should not go ignored.

also (e.g Kiviniemi and Duangdoo, 2009; Lawton, Connor and McEachan, 2009) and highlights the importance of positive emotions. As described in Chapter 3 ☛, health researchers are guilty sometimes of focusing on demographic, social and cognitive factors (e.g. Chapter 5 ☛ describes some of the key models of wider sociocognitive influences on behaviours such as eating or exercise) and of not paying sufficient attention to the powerful role of emotion.

Unfortunately, tasting 'good' often appears to correlate with sugar and fat content rather than with healthy food, and preconceptions exist about healthy food that can work against a person making healthy food choices. For example, 37 per cent of Haste's sample agreed with the statement 'Healthy food usually doesn't taste as good as unhealthy food'. Where do these preferences and perceptions come from?

## Food preferences

While food preferences have a biological basis, they are also significantly determined by social and cultural factors (Pfeifer, 2009). Children learn by example and thus parents play a major role in setting down patterns of eating, food choices and leisure activities among their children. Parents develop the rules and guidelines as to what is considered appropriate behaviour, and these have been variously associated with children's eating behaviour. For example, parental permissiveness was associated with less healthy eating behaviour among adolescents and young adults (Bourdeaudhuij, 1997; Bourdeaudhuij and van Oost, 1998), and child-centred feeding practices including reasoning and praising related positively to fruit and vegetable intake in contrast to parent-centred feeding practices including warning or physically struggling to get a child to

**Photo 4.1** 'We are what we eat?' The importance of providing positive norms for healthy eating in children

*Source*: Alexandros Michailidis/Shutterstock.

eat these food types (Vereecken et al., 2010). Food preferences are initially learned through socialisation within the family, with the food provided by parents to their children often setting the child's future preferences for:

- *cooking methods*: e.g. home-cooked/fresh vs. ready-made/processed;
- *products*: e.g. high-fat vs. low-fat, organic vs. non-organic;
- *tastes*: e.g. seasoned vs. bland, sweet vs. sour;
- *textures*: e.g. soft–crunchy, tender–chewy;
- *food components*: e.g. red/white meat, vegetables, fruit, grains, pulses and carbohydrates.

Various interventions have targeted the fruit and vegetable intake of young people, such as the Food Dudes programme developed in North Wales, which has subsequently targetted pre-school and primary-school children in the UK, Ireland and elsewhere in Europe (Tapper et al., 2003; Horne et al., 2004, 2009, 2011; Lowe et al., 2004). This programme draws on established learning theory techniques of increased taste exposure to fruit and vegetables, modelling of healthy behaviour through cartoon youth characters (see Photo 4.1), and reinforcement by means of child-friendly non-food rewards (e.g. stickers, crayons) for eating the fruit and vegetables provided at snack and meal times (Lowe et al., 2004). Long-term effectiveness of the peer-modelling and rewards-based intervention on the fruit and vegetable consumption of children was found, with particular gains among those children who ate less fruit and vegetables at the study outset (Horne et al., 2009). These findings have also been replicated in the USA (Wengreen et al., 2013) where biophysical measurements supported self-report measures to demonstrate increased fruit and vegetable intake. Simply increasing exposure to, or availability of, healthy food options, is insufficient however, as seen in a randomised controlled trial of having fruit 'tuck shops' in primary schools where no increase in fruit consumption was found (Moore et al., 2000; Moore, 2001). More recent evidence suggests that enabling messy play with foods, or enabling multisensory exposure to foods without the need to taste, such as via involvement in cooking or growing food, or gaming, can promote liking for new foods and subsequently tasting (Coulthard and Ahmed, 2017; Farrow and Haycraft, 2019). It must be noted in conclusion though that even knowing what constitutes healthy eating, does not guarantee healthy food choices in young people (or adults!), and modelling can of course work both ways i.e negative modelling where peers are seen to reject certain foods.

Given the challenge of increasing fruit and vegetable intake sufficiently, some have turned to supplementing their diet with antioxidant vitamins (e.g. vitamins A, C and E; beta-carotene; folic acid), also thought to have health benefits (see 'Issues').

## ISSUES

### Do vitamins protect us from disease?

Vitamin supplementation has become a growth industry – just look at the shelves of your local supermarkets or pharmacist. Why?

#### Claims

Research has suggested that a lack of vitamins A, C and E, beta-carotene and folic acid in a person's diet plays a role in blood vessel changes that potentially contribute to heart disease, and low beta-carotene (found in carrots, sweet potatoes) has been linked with certain cancers (see Bardia et al., 2008, for a systematic review and meta-analysis). Such associations are attributed to the antioxidant properties of these vitamins (i.e. they reduce the oxidated products of metabolism which can cause cell damage). We now understand that cooking these vegetables releases these vitamins more easily for absorption than eating them raw. Additionally, vitamins C and E have anti-inflammatory effects. Both inflammation and oxidation have been linked with cognitive decline and progression towards dementia. Naturally, such findings stimulate media and public interest, and taking vitamin supplements as a means of protecting one's health has become commonplace.

*(continued)*

## Evidence

However, what is the evidence base as to their effectiveness? Do supplements work in the same way as when contained naturally in the foods we eat? The United States Preventive Services Task Force (USPSTF: an expert group formed to review research evidence in order to make informed health recommendations) conducted two large-scale reviews of studies of vitamin supplements – one in relation to reduced risk of cardiovascular disease (USPSTF 2003) and the other in relation to reduced risk of breast, lung, colon and prostate cancer (Morris and Carson, 2003). They found that in terms of subsequent development of disease, even well-designed randomised controlled trials comparing vitamin supplements with an identical-looking placebo pill were inconclusive in their findings. Worryingly, they find 'compelling evidence' of an increase in lung cancer risk and subsequent death in smokers who take beta-carotene supplements. However, Bardia et al. (2008) concluded from their review of 12 randomised trials (9 with high methodological quality, overall related to 104,196 individuals) that even this evidence regarding mortality is limited because not all trials analysed mortality data by whether their sample smoked or not! Quite an important omission.

Notably, the stronger claims of associations between vitamin supplements and reduced disease risk come from more poorly designed and poorly controlled studies, for example, **observational studies** reporting an association between vitamin A intake and reduced breast cancer incidence generally failed to control for important factors such as general diet or levels of physical activity. Consistent with the USPSTF report, Bardia et al.'s review concludes that there was no effect of antioxidant supplementation in relation to primary cancer incidence and mortality. In making their recommendations, the USPSTF concluded that, with the exception of advising against smokers taking beta-carotene supplements, there was little evidence of vitamin supplements causing harm, BUT neither was their conclusive evidence of benefits in terms of reduced risk of heart disease or many forms of cancer.

In terms of the potential of vitamin C and E supplements to halt cognitive decline, the evidence is also mixed. Plassman et al.'s (2010) review of 127 observational studies, 22 randomised controlled trials and 16 systematic reviews included seven studies which specifically addressed whether cognitive decline was related to these nutritional supplement and found insufficient evidence to support such an association. Overall antioxidant supplementation did not slow cognitive change over a five-year period among women with pre-existing cardiovascular disease or cardiovascular disease risk factors, but an effect of vitamin C or beta-carotene intake was found among a sub-group who had low dietary intake levels (Kang et al., 2009). It may be that effects are confined to specific populations. Given that cognitive decline and dementias are increasingly prevalent in an ageing society, more rigorous and focused studies with less varied populations are justified.

Overall, therefore, current research no longer supports the taking of antioxidant supplements, except perhaps where natural food sources are lacking. Eating a healthy diet with these vitamins contained within the foodstuffs and maintaining a healthy body weight are more relevant to reducing disease risk than relying on supplements. Further study, that controls for lifestyle and sample characteristics and that considers the interactions between the various antioxidant components and micro- and macro-nutrients contained within such supplements, is justified. This will lead to a more robust evidence base and also help determine any critical ingredients or composition.

### observational studies

research studies which evaluate the effects of an intervention (or a treatment) without comparison to a control group and thus such studies are more limited in their conclusions than randomised controlled trials

# Exercise

Physical inactivity has been identified by the World Health Organization as the fourth leading risk factor for global mortality. As we will describe here, regular exercise (physical activity) in contrast is generally considered as health-protective, reducing an individual's risk of developing diseases such as cardiovascular and coronary heart disease, type 2 diabetes mellitus, osteoporosis and obesity, and some forms of cancer, including colorectal and breast cancer (WHO, 2018b).

As a result, most countries have guidelines as to what is considered the appropriate amount of exercise to gain health benefits.

## Recommendations to exercise

Specific recommendations regarding physical activity required to achieve good physical and mental health have been made by the UK nations Chief Medical Officers (Department of Health and Social Care, 2019). For younger children aged 1–5 years this proposes a variety of activity for up to three hours a day, with a specified moderate intensity hour for those aged 4–5. For children aged 5–18 years, a very wide age band, the recommendation is for at least 60 minutes of moderate to vigorous activity every day. For adults (aged 18–64 years) being active every day is recommended with an accumulation of 150 minutes of moderate intensity activity and 75 minutes of vigorous activity suggested which should include muscle strengthening exercise on at least two days (Department of Health and Social Care, 2019). For those over 65 years of age, the guidelines are the same as for younger adults although specific recommendations include balance-enhancing exercise for those with limited mobility.

The aim of such guidelines is to set minimum activity targets with the potential to reduce the incidence of the diseases described above, including obesity, as well as improving general wellbeing. Guidelines are not intended to be set so high as to be beyond the reach of the average individual, and certainly the advice for a previously inactive individual is to build up their exercise levels gradually, rather than making dramatic changes to the frequency or intensity of exercise performance. Furthermore, where a pre-existing health complaint exists, plans to become more active should first be discussed with a medical professional. The popular 10,000 steps a day walking target, which approximates to 5 miles at an average stride-length, is promoted by popular 'wearable technologies (smart phones, watches). However the research evidence of the health benefits of this number of steps versus say 8,000 or 5,000 remains limited given variation in the speed and intensity with which different people take steps for example, or the different terrains on which people walk (Bassett et al., 2017; Dwyer et al., 2017; Lee et al., 2019). However the 10,000 steps movement has proven a useful 'cue' to behaviour and has at least raised awareness of the need to lead less sedentary lives.

In spite of obvious health benefits and active campaigning on the part of public health authorities to encourage people of all ages to become more active, exercise levels in some populations remain low.

## Levels of exercise

There is some suggestion that levels of childhood activity influence adult health and disease risk although there is need for more longitudinal research to confirm the pathways through which any effects occur (Hallal et al., 2006; Mattocks et al., 2008). It may be that active youngsters maintain activity in adulthood, but it may also be that active youngsters' lifestyles vary in other (healthy) ways as they grow older – whichever explanation it may be, there is certainly no harm in setting down patterns of healthy behaviour early.

The prevalence of inactivity is high in younger children. For example, the Millenium Cohort study which is tracking the health of over 6,000 UK children born between 2000 and 2002 (Griffiths et al., 2013) reported that when aged 7 years old, fewer than half were engaging in recommended levels of activity, with girls again less active than boys (38 per cent vs. 63 per cent meeting guidelines).

Global data has shown that the majority of young people aged 11–17 years report insufficient physical activity. For example, data from 298 school-based surveys which included 1.6 million children from 146 countries or territories, revealed that between 2001 and 2016 the prevalence of insufficient activity decreased for boys (from 80.1 per cent insufficiently active to 77.6 per cent) which is encouraging, however there was no such decrease for girls (85.1 per cent, 84.7 per cent in 2001 and 2016 respectively) (Guthold et al., 2020). Data from England has shown two-thirds of adults to be active as per the guidelines, but with inactive levels increasing with age (see Figure 4.2).

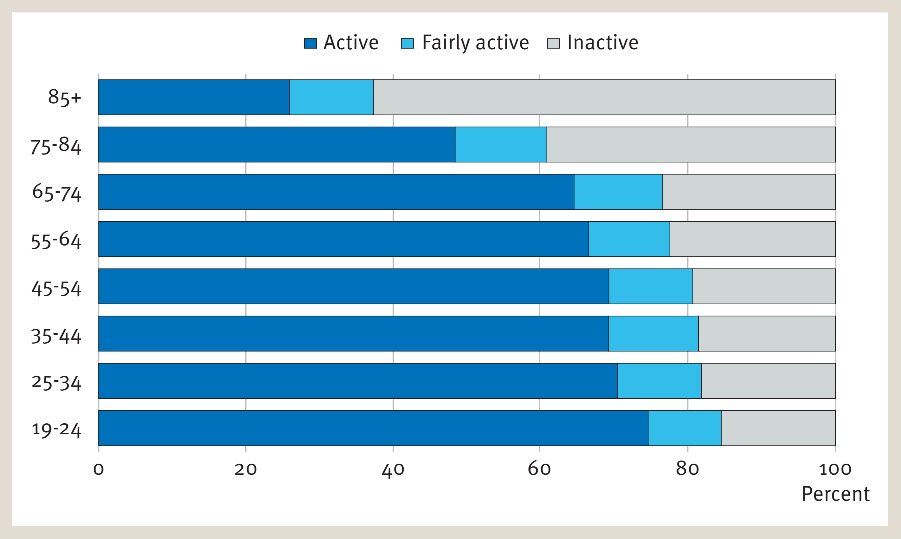

**Figure 4.2** Age and activity levels (England only data), 2018

*Source*: https://digital.nhs.uk/data-and-information/publications/statistical/statistics-on-obesity-physical-activity-and-diet/statistics-on-obesity-physical-activity-and-diet-england-2019/part-5-adult-physical-activity.

A greater percentage of young adults (16 to 24 years) typically meet current recommended physical activity levels compared with much older adults, but insufficient activity levels are still high (WHO, 2018b). Globally, among those aged over 18 years data suggests that over a quarter are insufficiently active with some regions e.g. the Americas being higher than average (see Table 4.1). As presented in Table 4.1, the prevalence of insufficient physical activity in World Health Organization regions also shows that women are generally found to be more inactive than men. Typically also older women are less active than younger women (e.g. Stephenson et al., 2000), although data on the behaviour of the 'very old' (i.e. 85+) are limited by many surveys simply comparing people who are under 65 years of age with those aged over 65. In older populations exercise behaviour is likely to be influenced by factors such as current health status and physical functioning, access to facilities, and even personal safety concerns (in terms of walking alone, or of accidents at the gym). However, a person's lifespan (longevity) may be predicted by the extent to which a person is physically active as we describe in the next section.

**Table 4.1** Prevalence of insufficient physical activity in adults aged over 18 years (age standardised %) (2016)

| Region | Both sexes | Male | Female |
|---|---|---|---|
| Global | 27.5 | 23.4 | 31.7 |
| Africa | 22.1 | 18.4 | 25.6 |
| Americas | 39.3 | 33.1 | 45.2 |
| South-East Asia | 30.5 | 22.9 | 38.3 |
| Europe | 29.4 | 26.2 | 32.4 |
| Eastern Mediterranean | 34.9 | 26.9 | 43.5 |
| Western Pacific | 18.6 | 18.8 | 18.5 |

*Footnote*: Insufficient PA defined as less than 150 minutes of moderate-intensity physical activity per week, or less than 75 minutes of vigorous-intensity physical activity per week, or equivalent

*Source*: https://www.who.int/data/gho/indicator-metadata-registry/imr-details/2381.

Within these wide geographic regions are national variations with influences seen of age, of gender, and of socioeconomic status. In addition, cultural differences have also been reported among both adults and children. For example, Bangladeshi, Pakistani and Indian (South Asian) participants are significantly less active than white participants (adults aged over 55 living in the UK in the Health Survey for England, Williams et al., 2011; adults screened for type 2 diabetes, Yates et al., 2010; and children aged 7, Griffiths et al., 2013). That ethnic variations in physical activity exist points also to wider influences on activity which have been described in Chapter 2 ☛, i.e. that of socio-economic inequalities in terms of access to sports and leisure facilities, and social inclusion for those of BME status, at least in the UK.

## What are the physical health benefits of exercise?

The extent and nature of the physical health benefits of 'exercise' or 'activity' will very much depend on how it is defined and how it is measured. We use the term 'exercise' broadly here, encompassing both planned physical activity such as going swimming or to the gym for an exercise 'class', planned leisure activity such as dancing or going for a walk, and that which is simply physical activity generated by body movement in the pursuit of one's daily life such as when going shopping or doing heavy housework. The majority of research studies in this domain have focused on the presence of purposeful exercise. However, exercise does not have to be structured and formal; there is clear evidence from a meta-analysis of randomised controlled trials that simply regular walking can reduce the risk of cardiovascular disease, particularly among older people (Murphy et al., 2007). Sedentary lifestyles, even in terms of those whose working life means that they sit for most of the day (as is the case with many academics!) have been associated with reduced life expectancy (Buckley et al., 2015). Sedentarism can also increase social isolation which has risks to psychological health as discussed below.

There is consistent evidence that regular physical activity provides physical and psychological benefits to those with long-term conditions (LTC), for example chronic pain (Geneen et al., 2017) – and given that over a third of the adult population may live with an LTC (UK data, ONS, 2020a), this evidence is a significant cue to development of physical activity interventions. Several studies have shown an inverse relationship between habitual physical activity and multi-morbidity, i.e. the coexistence of several health conditions (Autenrieth et al., 2013; Cimarras-Otal et al., 2014).

The benefits of exercise for those with existing disease includes for example, increasing muscular strength, enhancing physical function and quality of life, reducing fatigue and the side effects of cancer treatments (Cramp and Daniel, 2008; Perna et al., 2008) and reducing fatigue in those with Chronic Fatigue Syndrome (White et al., 2011).

As well as benefitting those with existing disease, regular exercise is also protective against the development of some conditions. One example where the evidence base is consistent is that of osteoporosis, a condition characterised by a reduction in bone density due to calcium loss, which leads to brittle bones, a loss of bone strength and an increased risk of fractures. It is estimated that, in the UK, someone experiences a bone fracture due to osteoporotic bones every two minutes, and that one in two women and one in five men over the age of 50 will have this condition (Royal Osteoporosis Society, 2019). Regular exercise, particularly low-impact exercise or weight-bearing exercise such as walking and dancing, helps in the laying down of calcium in the bones, which helps to prevent bone thinning and fractures (Pinheiro et al., 2020). Exercise is therefore not just important to bone development in the young but is also important for maintaining peak levels of bone density during adulthood. Additional benefits to muscle strength, coordination and balance can be gained from resistance-strengthening exercise, which in turn can benefit older individuals by reducing the risk of falls and subsequent bone fractures (Royal Osteoporosis Society, 2019).

Even among overweight individuals with a body mass index (BMI) (see Chapter 3 ☛) of 25.0 or more – being of moderate or high 'fitness' can significantly reduce overall mortality and heart attack incidence compared to overweight individuals who are also of 'low' fitness (Ortega et al., 2018). Being 'fat' does not inevitably mean being metabolically 'unfit' and fitness may offer some protection against negative effects of being overweight. Also BMI is considered a crude measure, with increasing recognition that body fat percentage (adiposity) and its distribution around the body (e.g. waist

**Photo 4.2** Public Health England's Change4Life initiative has become one of the most instantly recognisable brands in health improvement.

*Source*: Department of Health. (This logo will be revamped by the end of 2021).

circumference) is important. For example, using data from the large UK Biobank study, a significant association was found between adiposity and the incidence of post-menopausal breast cancer, and endometrial cancers (women), and with colon cancer (men) even where the sample consisted of those of normal weight according to BMI (Arthur et al., 2021).

In general, regular exercise is an accepted means of reducing one's risk of developing a range of serious health conditions, including type 2 diabetes, stroke, CHD and some forms of cancer (e.g. colon) (Department of Health and Social Care, 2019). Once a relationship between a behaviour and a health outcome has been established, it is important to ask 'how' this relationship operates. In terms of exercise and reduced heart disease risk, it appears that regular performance of exercise:

- strengthens the heart muscles;
- increases cardiac and respiratory efficiency
- tends to reduce blood pressure;
- reduces the tendency of a person to accumulate body fat.

Exercise helps to maintain the balance between energy intake and energy output and works to protect physical health in a variety of ways. However, as found among healthy individuals, a range of factors will predict whether clinical populations will engage in sufficient physical activity to reap the benefits (see 'Why do people exercise' below). A 'dose–response' relationship is seen to exist in relation to reduced risk of cardiovascular disease, type 2 diabetes and some forms of cancer, whereby the greater the level (frequency and intensity) of exercise, the greater the benefits.

Rhodes et al. (2017) note that, although increasing levels of physical activity are generally linked to more positive health outcomes the most pronounced impacts are seen in those with very low levels of physical activity who start to do some more activity i.e becoming active confers more benefits than increasing activity in those already active at a good level. However, definitions of the required levels of physical activity in health recommendations as we have described above tend to focus on much higher levels of required physical activity.

Finally, it is worth noting, in relation to the aforementioned dose–response association, extreme exercise dependence is sometimes associated with a poor body image and with other compulsive disorders including eating disorders (e.g. Hamer and Karageorghis, 2007; Cook and Hausenblas, 2008), and there is also the risk of injury and musculoskeletal damage (see later).

## The psychological benefits of exercise

### Exercise and mood

Exercise has been associated with psychological benefits in terms of elevated mood among wide and varied populations. Although findings are often from non-controlled, correlational studies, they have contributed to recommendations that exercise be included as a treatment for depression, for example in NICE guidelines (NICE, 2007). This guidance has been supported in a meta-analysis of data obtained from 23 randomised controlled trials where exercise was provided as an intervention to those with depression (compared to a control intervention or no treatment). A large clinical benefit of exercise in terms of reduced depressive symptomatology was reported. However, it is important to note that this effect reduced to a moderate and non-significant effect when the three most robust/highest quality studies were meta-analysed – exercise in these studies did no better than cognitive therapies (Mead et al., 2009). This highlights the importance of drawing conclusions from well-controlled, prospective studies rather than single correlational studies.

Regular exercise of a moderate intensity has also been associated with reduced anxiety and depression and improved self-esteem or body-image among nonclinical populations, including in a meta-analysis of 121 mixed design studies (Hausenblas and Fallon, 2006) and in experimental studies (e.g. Crush et al., 2018). Single episodes or limited-frequency aerobic exercise appear beneficial also in terms of elevated mood, self-esteem and **prosocial behaviour** (Biddle et al., 2000; UK Department of Health, 2005). These psychological benefits of

**prosocial behaviour**
behavioural acts that are positively valued by society and that may elicit positive social consequences

exercise have been attributed to various biological mechanisms, including:

- exercise-induced release of the body's own natural opiates – endorphins – into the bloodstream, which produce a 'natural high' and act as a painkiller, and reductions in the stress hormone, cortisol (Duclos et al., 2003) (Chapter 12 ☛);
- stimulation of the release of **catecholamines** such as **noradrenaline** and **adrenaline**, which counter any stress response and enhance mood (Chapters 8 and 12 ☛);
- muscle relaxation, which reduces feelings of tension.

Rhodes and Kates (2015), following a systematic review of 24 studies noted that the timing of improved mood/positive affect is important in relation to maintaining exercise in future positive affect experienced DURING the exercise was predictive of future activity, whereas positive affect experienced after exercising did not. Further complexity in the relationship between exercise and positive mood exists in the evidence of an inverse relationship between exercise intensity and adherence: individuals are less likely to maintain intense exercise than moderate exercise, possibly because it is experienced as adversive (Brewer et al., 2000). This suggestion that, beyond a certain level, exercise may in fact be detrimental to mood was explored further by Hall et al. (2002) who examined the **affective** response of 30 volunteers to increasing levels of exercise intensity. Their results showed not only that intense exercise caused negative mood but also that the timing of mood assessments (pre and post-exercise assessment, compared with repeated assessment during exercise) profoundly changed the nature of the relationship found. Studies measuring mood before exercise, and again after exercise has ended and the person has recovered, generally report positive affective responses. However, Hall and colleagues' data clearly show considerable mood deterioration as exercise intensity increases, with mood rising to more positive levels only on exercise completion. These authors propose that remembering the negative affective response experienced *during* exercise is likely to impair an individual's future adherence (the converse of positive affect effects as described by Rhodes and Kates, 2015), and that this may explain why some studies report poor exercise adherence rates. Such findings highlight the need for researchers to consider both the timing of assessments and also that, because exercise is an event that typically takes time, a person's experience of it may also change over the course of its performance (Ekkekakis et al., 2008). Mood is a complex phenomenon!

Many other factors may combine with biological factors to influence the affective experience reported. Exercise may offer cognitive distraction or actual physical removal from life's problems, and as such provide a means of coping with stress. During exercise, a person may focus on aspects of the physical exertion or on the heart-rate monitor, they may distract themselves by listening to music or planning a holiday, or they may use the time to think through current stressors or demands and plan their coping responses (see Chapter 12 ☛). For others, the social support gained from exercising with friends plays an important role, particularly for females (Molloy et al., 2010). Even the exercise environment itself can play a role in mood outcomes, such as room temperature, the presence and type of music, and the presence of mirrors – the latter being associated with negative wellbeing (Martin Ginis et al., 2007).

For some individuals, self-image and self-esteem may be enhanced as a result of exercise contributing to weight loss and general fitness. Hausenblas and Fallon (2006)

**catecholamines**

these chemical substances are brain neurotransmitters and include adrenaline and noradrenaline

**noradrenaline**

this **catecholamine** is a neurotransmitter found in the brain and in the **sympathetic nervous system**; also known as **norepinephrine**

**adrenaline**

a neurotransmitter and hormone secreted by the adrenal medulla that increases physiological activity in the body, including stimulation of heart action and an increase in blood pressure and metabolic rate; also known as epinephrine

**sympathetic nervous system**

the part of the autonomic nervous system involved in mobilising energy to activate and maintain arousal (e.g. increased heart rate)

**affective**

to do with affect or mood and emotions

noted in their review and meta-analysis that exercisers had a more positive body image than non-exercisers, which does however raise the question of cause and effect unless the data collected is prospective i.e. follows people from non-exercising to exercising. It could be that people with greater self-esteem take part in exercise in the first place. Rightly or wrongly, we live in a society where trim figures are judged more positively (by others as well as by ourselves) than those that are considered to be overweight or unfit and being 'not-trim' can act as a barrier to initiating exercise, particularly formal gym classes.

## Exercise and cognitive function

Exercise may have psychological benefits for those experiencing cognitive decline as a result of ageing or dementia. Cotman and Engesser-Cesar (2002) reported that physical activity was associated with delays in the age-related neuronal dysfunction and degeneration that underlies types of cognitive decline often associated with Alzheimer's disease, such as memory lapses and not paying attention. Physical activity may improve at least some aspects of cognitive function important for tasks of daily living by virtue of neuroprotective effects, although the evidence on this is relatively new. For example, reviewing evidence of the effects of exercise on those identified with mild cognitive impairment (MCI, defined as atypical cognitive decline given a person's age and educational level which confers risk for going on to develop dementia) Barber and colleagues conclude that the neurobiological and vascular processes (increased cerebral blood flow) attributed to exercise have some evidence base from anatomical studies using MRI brain scans, reasonable evidence from general population studies comparing cognitive decline in the active versus the inactive, and finally, encouraging but as yet limited evidence from randomised controlled trials of physical activity interventions (Barber et al., 2012).

## IN THE SPOTLIGHT

### Exercise, our genes and ageing

A great example of health research moving from the laboratory run by cell biologists to potentially the interface with patients and health behaviour change interventions is the growing body of work exploring the association between our DNA and ageing. Telomeres are protective caps, made up of a combination of DNA and protein, based on the ends of cell chromosomes. Telomeres are involved in protecting DNA during naturally occurring cell division but they become shorter as we age and their structural integrity weakens, and the cells age (lose their DNA) and die quicker (a process known as cell senescence). This process can accelerate our aging.

Telomeres exist in all cells but in relation to telomeres and exercise, research has focussed on those within our leukocytes (and within our skeletal muscle cells). Evidence from several prospective studies, both in animals and in humans, has shown that shorter telomeres and lower levels of teleromase, the enzyme responsible for repair and lengthening of telomeres, is associated with a broad range of diseases. This includes many forms of cancer, infectious diseases, stroke, vascular dementia, cardiovascular disease, obesity, osteoporosis and diabetes, and increased overall mortality risk. Along with colleagues at the University of California, San Francisco, Elizabeth Blackburn (a Nobel prize-winning scientist) has conducted many longitudinal studies among the healthy and patient groups, in both younger and older populations to examine why these associations may exist. Summaries of this exciting avenue of work are available in a lecture series available on YouTube, making this science widely accessible (see for example, https://www.youtube.com/watch?v=-INR1xZS5GY)

In exploring *why* there may be an association between telomere length and disease, or even survival, several possible behavioural and psychosocial factors have emerged, including exercise and perceived stress (including caregiving stress) (see Chapter 15 ☛). One example is a pilot study by Ornish and colleagues (2013) which followed 35 men with early stage, localised prostate cancer over five years, ten of whom were asked to make lifestyle changes in terms of their exercise levels, diet, use of social support and stress management. Compared to the 25 not making lifestyle changes, blood samples taken at five years found that their telomere length *grew* by approximately 10 per cent, compared to approximately 3 per cent shortening in the control group. In addition, a linear relationship was seen between the extent of lifestyle change and the percentage increase in length. No significant association was found between lifestyle change and telemorase enzyme levels, however. More recently, Arsenis et al.'s review (2017) summarised evidence of longer telomere length among those who exercise, and among athletes, and highlight that among older individuals who exercise the benefits to telomere health are greater. When trying to summarise the mechanisms underlying the protective and restorative effects of exercise on telomere health, Arsenis points to the increasing teleromase levels reducing levels of oxidative stress and inflammation (i.e. processes seen in chronic health conditions and in obesity) and skeletal muscle preservation. It appears that being active and losing weight can increase telomere length and that this could benefit healthy ageing, but many more experimental studies are needed before we will fully understand the interacting effects of genes, our behaviour, and ageing.

## Why do people exercise (or not)?

People who choose to exercise cite a variety of reasons for doing so, including, most commonly:

- desire for physical fitness;
- desire to lose weight, change body shape and appearance;
- desire to maintain or enhance health status;
- desire to improve self-image and mood;
- as a means of stress reduction;
- as a social activity.

These conscious motives have been frequently evidenced, but non-conscious motives may also exist, such as those created by prior improvements in positive affect experienced when exercising (van Cappellen et al., 2018).

It is also not to be inferred that choosing not to exercise reflects an absence of the types of desire, motives or goals listed above. Many perceived barriers exist that contribute to people's reasons for not exercising, even when they simultaneously report, for example, a desire to lose weight. Barriers commonly mentioned include:

- lack of time;
- cost;
- lack of access to appropriate facilities and equipment;
- embarrassment;
- lack of self-belief;
- lack of someone to go with to provide support.

Research has identified common clusters of reasons for choosing to exercise or not to exercise, although the extent to which this evidence is currently used to usefully inform intervention programmes has been questioned (e.g. Brunton et al., 2003). For example, busy routes, traffic congestion, and low cycle awareness in drivers, and no cycle paths are environmental barriers to a cycling commute that compound any personal or motivational barriers to exercise (e.g. Timperio et al., 2006), yet few countries have sufficiently adapted their towns and cities. Among older samples, having more positive views of the meaning and implications of ageing was associated with more regular walking and increased walking over time among adults aged 65–85 studied by Wurm and colleagues (Wurm et al., 2010), yet we continue to witness negative stereotypes of ageing. In the 'Research focus' we highlight the part played simply (but rarely considered) by acceptability – we should not assume that physical activity is considered acceptable or valuable to older adults.

Not surprisingly perhaps, the beliefs and attitudes towards exercise held by those who are active differ from those who are not active (see also 'Issues'). Those who exercise regularly are more likely to perceive (and report) positive outcomes of exercise than those who do not; perceive fewer barriers to exercising, and believe that

## RESEARCH FOCUS

### How acceptable do older adults find the concept of being physically active? A systematic review and meta-synthesis

McGowan, L. J., Devereux-Fitzgerald, A., Powell, R. and French, D. P. (2018). How acceptable do older adults find the concept of being physically active? A systematic review and meta-synthesis, *International Review of Sport and Exercise Psychology*, 11:1, 1–24

As described in this chapter, physical activity (PA) has known benefits for our physical and mental wellbeing. However, the extent to which individuals engage in sufficient amounts of it to reap these gains has many influences. The physical activity levels of those aged 65 or more frequently fall short of national and WHO recommendations, and typically declines further with age. Interventions seeking to increase engagement in PA among healthy, or non-clinical populations of older adults are commonly based on research findings drawn from younger adult populations and target self-regulatory behaviours such as self-monitoring or goal-setting. McGowan and colleagues present evidence from their earlier work that such interventions have achieved limited success in older, as compared to younger populations and suggest that this may be because the goals of PA differ for different ages. Barriers to, and facilitators of PA are commonly identified by quantitative means (using checklists for example) rather than exploring the meanings and perspectives older adults take towards being physically active. If interventions are to succeed they have to be acceptable and appropriate to the target population and their goals.

### Aims and methods

To explore such questions the authors review and synthesise *qualitative* evidence from studies addressing perceptions of PA held by older adults who are not already participating in intervention studies (to avoid inherent bias among those willing to engage in PA). English-language qualitative studies, published since 1970 were included. Search terms were compiled using the SPIDER tool which considers **S**ample; **P**henomenon of **I**nterest; **D**esign; **E**valuation and **R**esearch type, with illustration of each component below:

**S**ample: older adults, aged 65 years or above, living independently in the community

**P**henomenon of **I**nterest: acceptability of engagement in PA for older adults not currently active or involved in an intervention

**D**esign: qualitative research methods including interviews, focus groups, and open-ended questions

**E**valuation: acceptabiliity, feasibility, perceptions, attitudes, views, beliefs, barriers, motivation

**R**esearch type: qualitative or mixed method studies where qualitative data are analysed and reported separately to any quantitative findings

Four searches were conducted (PsychInfo, Medline, CINAHL and AMED) with methods of the searches, title and abstract screening and full text paper retrieval clearly described. Data extraction and quality appraisal was applied to the ten eligible studies identified from 1,198 initial records retrieved. Reasons for study exclusion are presented in a screening flowchart as is typical for a systematic review.

Quality appraisal of the selected studies employed the CASP tool specific to qualitative research whereby rigour, credibility and relevance of the qualitative work to the research objectives are evaluated. Five studies were judged to be of high quality, three as medium, and two of low quality. Data was extracted from each paper regarding study aims, sample size, sample ethnicity, country of study, data collection method, and type of qualitative analysis.

The extracted results or findings (participant quotes, author interpretations) were subjected to a thematic synthesis which involves three main stages (useful appendices detail each stage):

a. inductive line-by-line coding of the findings to encapsulate meaning, with codes split or merged where concepts were considered to be semantically similar or different

b. codes are refined or grouped inductively to produce ‘descriptive’ themes
c. a more deductive final stage involved analysing the descriptive themes directly in relation to the research questions, identifying processes underlying themes and according to the researcher’s judgement in order to generate new interpretative conclusions which were discussed within the wider research team prior to constructing the final narrative.

## Findings

Five studies were conducted in the USA (two included specific ethnic groups), and one each in Australia, Canada, Republic of Ireland, Scotland and Sweden. Only one study considered socioeconomic differences. The primary focus of 9/10 studies was older adults’ perceptions of physical activity, the 10th investigated determinants of and motivations to reduce sedentary behaviour.

Seven descriptive themes were identified:

- Personal motivations for PA
- Intrapersonal constraints for PA
- Perceptions of ageing
- External sources of encouragement
- Knowledge and beliefs about PA
- Influence of environmental factors

From these seven, three broader analytical themes were derived:

1. Older adults’ construal of PA
2. Self-identity and roles within the wider society
3. Perceived vulnerability vs. maintaining control

The authors describe data pertaining to three analytical themes which are not mutually exclusive i.e. a descriptive theme or subtheme can feed into one or more analytic themes, for example ‘perceptions of ageing’ fed into all three analytic themes.

1. When examining the construal of PA, several studies described how the distinction between PA and exercise was often unclear and inconsistent, with terms often used interchangeably. PA was seen as including doing house or garden chores or walking the dog, and as such appeared to be considered a by-product of activities of daily living rather than purposeful exercise. Others however described exercise as any activity involving movement. One study comparing Asian Indians living in the USA rather than in India elicited views of non-Western cultures considering exercise as inherent to living their lives without transport or other infrastructure (e.g. walking to school and work, queuing for food in rural India), whereas they believed other/Western cultures to be more sedentary and thus needing to make separate time for purposive exercise. (The issue of sedentarism is discussed earlier in the chapter).

   Barriers to PA were often cited as environmental (weather, poor surfaces) which suggests that older adults implicitly construed PA as something to be done outdoors, and not perhaps as something structured around an indoors gym. Participants generally displayed good understanding of the physical and mental health benefits of being physically active, while not necessarily pointing to benefits of any specific activity. Overall it seemed that older adults did not view physical activity as a primary goal but rather a by-product of their carrying out other meaningful and valued activity.
2. In terms of self-identity, purposeful PA appeared less relevant to the values, goals and commitments of adults who saw themselves as ageing, and who also perceived that others viewed them as ageing members of society for whom PA was less relevant or incompatible. Exercise to reap future health benefits was questioned in terms of value and relevance to their self-identity and life stage, whereas PA that brought enjoyment, social connectedness, or made them feel useful, was valued. PA goals were more present-oriented, such as feeling useful by helping others, feeling connected and valued, or by demonstrating independence.

   PA was greater among those older adults who had previously been physically active and who had PA as an inherent part of their identity (or a ‘habit’) (see Chapter 5 ☛), although there was recognition that PA had to be modified to suit their ability or to avoid injury etc. The data demonstrated that older adults did not wish to be seen as a homogenous and

*(continued)*

self-constrained group within society. Participants were aware of the negative connotations of ageing and felt that ageism acted as a constraint to their being physically active (i.e. their being active would be unsupported or mocked). To avoid this potential discrimination some older adults actually preferred dedicated messaging or programmes of PA. Also seen in this theme of self-identity were those who felt that old age made some people lazy, positioned alongwith others who felt older adults had earned the right *not* to have to be physically active!

3. Older adults' desire to retain autonomy and control over their lives while recognising the vulnerabilities that can accompany their ageing. For some, PA provided an opportunity to demonstrate independence, although a fear of injury or falling and the influence of physical limitations on their confidence was a significant constraint to their levels of PA. Social constraints in their environment were reported alongwith a desire for, as with other age groups, having an activity partner.

## Discussion

In discussing these analytical themes, the authors highlight the key points around PA as a by-product of other life activities; the issue of self-identity and others' perceptions of ageing and PA, and how older adults strive to balance ageing vulnerabilities with retaining independence through remaining physically active. This review presents findings that are complementary to two previous reviews, presenting a deeper level of analysis using data from samples who were not currently involved in PA interventions. For example, an earlier review by Devereux-Fitzgerald found that older adults placed greater value on PA than the current review sample- however their review included those who were engaged in PA or part of PA interventions including gym attendance or strength training. The perspectives not surprisingly differ. Who you draw a sample from is critical.

What is clear is that older adults want to be useful, independent but connected and valued, and to be seen by society as such. This study highlights some reasons for why PA guidelines for the older adult are not typically been met PA for activity's sake or directly for health reasons may not resonate with older adults whereas offering activity that involves social contact or enables them to feel useful and independent may be more attractive. Positive messaging around ageing and PA may also offer fruitful results, challenging both self, and societal, perceptions. Furthermore we know that reducing sedentariness has its own benefits (even without fully meeting PA requirements) thus the authors conclude this may be a useful target of future interventions.

Examination of the socioeconomic influences on perceptions and acceptability of PA (at all ages) and even though included studies were over-represented by females some note of whether primary analyses of any study addressed gender differences may have been illuminating. Nonetheless this review provides a useful synthesis of qualitative evidence and systematically describes both the review and analytic methods and thus it is worth a read.

exercising is under their own control. Such findings highlight the importance of 'getting people started'! Parental activity during a child's preschool years influences the child's concurrent activity (Hinkley et al., 2008) and also has a modest effect on increased child activity by the age of 11–12 (Mattocks et al., 2008). However, the effect of parental activity on the concurrent activity of older children is less consistent as peer influence takes on more weight (Sallis et al., 2000; Heitzler et al., 2006, 2010). There is a role for parental modelling and some scope for parental intervention for younger children, with different approaches taken for adolescents.

Of course, where there is a health-limiting condition, such as cancer, medical treatments and possible side effects, the energy to exercise (Arroyave et al., 2008), and motivations and beliefs such as self-efficacy for exercise (Gilliam and Schwebel, 2013) may be reduced. These individual health cognitions are discussed in more detail in Chapter 5 ☛.

Finally, as with many behaviours, exercise is perhaps best in moderation- the long-term physical consequences of excessive exercising which relate to muscle wastage and weight loss rather than to any specific disease are a reminder that even behaviour considered health-protective can carry risks when taken to the extreme. Exercise dependence has been associated with body image disorders and with eating pathologies (Cook and Hausenblas, 2008; Hausenblas and Symonds Downs, 2002).

## Health-screening behaviour

Screening is a growing part of preventive medicine across the industrialised world, with genetic testing becoming the ‘hot issue’ for the twenty-first century; however, screening is not without its challenges, as we shall describe below.

There are two broad purposes of health screening, each of which has implications for those involved:

1. identification of (behavioural and/or genetic) risk factors for illness to enable primary prevention via behaviour change, or, in the case of genetic risk, possibly prophylactic surgery;
2. to detect early asymptomatic signs of disease in order to treat or halt progression, leading to the person possibly facing regular medication or further investigations. This is akin to secondary prevention.

### WHAT DO YOU THINK?

What, if any, health-screening behaviour do you engage in?

Do you attend dental check-ups? Do you attend even when you have had six months without any symptoms of tooth decay? If not, consider your reasons for not doing so. If you receive a ‘clean bill of health’, how do you feel? Do you relax the way you look after your teeth due to feeling reassured that they are ‘healthy’?

Do you engage in any form of self-examination (breasts, testes)? If so, what made you start doing this? What would influence whether or not you would go to your doctor if you found something atypical? Chapter 9 ☛ further discusses symptom perception and responses such as seeking healthcare.

### Screening for risk factors

Screening for risk factors in those individuals thought to be healthy is based on the principle of susceptibility and, as such, it aims to identify an individual’s personal level of risk for future illness (and in the case of genetic testing, also in their offspring) in order to offer advice and information as to how to minimise further health risk, or to plan further investigation and treatment. Examples of such primary prevention include:

- screening for cardiovascular risk/risk of developing heart disease (cholesterol and blood pressure assessment and monitoring);
- prenatal genetic testing;
- genetic testing for carrier status of the cystic fibrosis, or Huntington’s disease gene, or for breast, ovarian or colon cancer, in those with a family history.

Bearing testimony to the importance of primary prevention, some community or worksite-based programmes offer blood pressure and cholesterol testing, along with an assessment of lifestyle factors and family history of heart disease. These assessments generate an index of general susceptibility, or personal ‘risk score’ related to potential morbidity and, if a person’s risk of disease is thought to be moderate or high, preventive measures can be suggested, such as dietary change or smoking cessation. It will become evident in later chapters that predicting behaviour change is highly complex (see Chapter 5 ☛), and thus interventions to change individuals’ risk behaviour face many challenges (see Chapters 6 and 7 ☛).

### Genetic screening

A range of diseases have a genetic component: for example, cystic fibrosis results from mutation to a single gene; Down’s syndrome results from chromosomal disorder; type 1 diabetes, breast and ovarian cancer, have multifactorial causes in that genetic damage may have an acquired cause (e.g. diet) as well as being inherited. With advances in the diagnostic technology for carrier status of genes predisposing to a range of conditions, such as breast cancer (e.g. mutations to the genes BRCA1 and BRCA2) (Sivell et al., 2007; O’Donovan and Livingston, 2010) or obesity (e.g. gene MC4R), arising from scientific research programmes such as the Human Genome Project (which ended in 2003), screening has perhaps become more controversial. While BRCA1 or BRCA2 mutations are responsible for breast and ovarian cancer in approximately 45–65, and 17–39 per cent respectively *of those individuals with an inherited susceptibility* to the disease (National Cancer Institute, 2009) such mutations are in fact relatively rare in the population, accounting for only 4-5 per cent of all breast cancer for example.

However, when compared to lifetime risk in those without the gene(s), of 12 per cent for breast cancer and 1.4 per cent for ovarian cancer, carrying these genes confers a significant increased risk (National Cancer Institute, 2009).

A review of studies of specific genetic testing for hereditary cancer found that between 60 and 80 per cent of the general population samples studied report high levels of interest in being tested (Braithwaite et al., 2002). Furthermore Ropka et al.'s (2006) systematic review of 18 studies of actual uptake decisions with regards to breast cancer screening as well as 40 hypothetical studies (of intention) found actual uptake to be just less than the hypothesised uptake (59 per cent vs. 66 per cent). An Australian study assessed interest in genetic testing for colorectal cancer among 300 Ashkenazi Jews, a population who have a higher risk of this multifactorial condition, and found that 94 per cent would have the predictive test, and a majority would make this decision out of a desire for information for their families as well as to decrease their own cancer risk through potentially changing lifestyle factors (Warner et al., 2005). Findings such as these show that interest in genetic testing is considerable which is perhaps not that unexpected given the increased risk such genes can carry.

Sivell and colleagues (2007) usefully summarised how genetic science had progressed, however science never stops, and further advances in genetic testing for cancer susceptibility are being made. Developments in new technologies which enable simultaneous testing of multiple susceptibilty genes (known as multiplex testing) are currently receiving attention (Domchek et al., 2013) and are exciting in their screening potential.

## Screening for disease detection

Screening for the purpose of disease detection is based on a biomedical model, which states that by identifying abnormalities in cell or organ functioning as early as possible, treatments can be implemented prior to the onset or advancement of disease symptoms. This is basically secondary prevention in that a specific screening test is offered to individuals identified as being at moderate to high risk of a certain condition on the basis of family history or, in some forms of population screening, age. The best-known examples of this are:

- screening for breast cancer (**mammography**);
- screening for cervical cancer (cervical smear or Pap test);
- PSA (prostate specific antigen) screening in males to identify levels as the marker for prostate cancer'
- antenatal screening, e.g. for Down's syndrome or spina bifida;
- bone density screening.

Population screening programmes typically exist for breast and cervical cancer in women, and for bowel cancer in both men and women. Breast cancer is the leading cancer type among women in the UK (over 400,000 cases per year across the EU), bowel cancer is the third most common cancer in both genders (World Cancer Research Fund, 2017). Cervical cancer screening exists because although cervical cancer is less common overall, it is the top ranked cancer in the under-35's and still over 100,000 women in EU countries (including the UK at the time) are diagnosed each year (WHO, 2018). Identifying these cancers at a pre-invasive stage, or at an early invasive stage can enable early treatment, with significant reductions to the associated mortality. The mortality rate associated with untreated cancer of the cervix is high (about 40 per cent).

Most European countries offer breast cancer screening, for example mammography is typically offered to woman aged 50–69 years old only (unless risk is identified in a younger woman) every three years. Among those screened less than 1 per cent are found to have an early cancer, although this itself can significantly reduce death rates associated with this disease (Hakama et al., 2008; Sarkeala et al., 2008). Screening younger women, however, appears less effective (and therefore also less cost effective) partly because there is a reduced incidence of breast cancer in this population, and also because the

mammography

a low-dose X-ray procedure that creates an image of the breast. The X-ray image can be used to identify early stages of tumours greater density of breast tissue make it more difficult to identify lumps within it. As cancer treatments have improved and mortality associated with breast cancer declined, concerns about false positives of mammography screening and the risk of unnecessary preventive treatment, the World Health Organization has stressed the importance of informed decision making based on knowledge of both the benefits and the risk (WHO, 2014).

In relation to cervical cancer screening, European statistics highlight national variation in the approach taken to the prevention and early diagnosis of cervical cancer, although half of the EU countries do have national screening programmes. Most Western countries invite adult women to cervical screening every five years, however more frequent screening is advised in some countries, for example, in Australia routine Pap smears (for all women) are recommended every two years, as is breast screening for women over 50. In the UK, regular 'smear tests' (Pap tests) are advocated from aged 25 until the age of 64. As well as screening for cell abnormalities, since 2019 samples taken in England are tested also for a viral infection known as HPV (human papilloma virus) which is itself a risk factor for cervical cancer. A large proportion of young, newly sexually active young women will acquire this viral infection and thus an early HPV vaccination is now available in most European countries for girls aged 9–13 years as recommended by the WHO (WHO, 2018c), and is also being provided to boys in some countries. This is expected to significantly reduce the incidence of cervical cancer– see below.

Bowel cancer screening is newer and exists in the form of a home-testing kit offered to adults aged 60–74 years every two years, although as part of the NHS Long Term Plan there are plans to reduce the age of receipt to 50 years. This testing kit is known as the 'poo-test' as it requires individuals taking a faeces sample. Coverage of bowel screening in England in 2019/20 was around 64 per cent, which compares to 72 per cent for both breast and cervical screening. The COVID-19 pandemic led to official national pauses and/or local suspensions of many screening programmes and worryingly it is estimated that over a million women will have missed the optimal time for breast screening, i.e. at early symptom onset, and that over a million bowel screening invitation letters will not have been sent (Nuffield Trust, 2021).

For men, prostate cancer is the most common form of cancer, accounting for more than a quarter of all cancer diagnoses in the UK in 2017 (World Cancer Research Fund, 2017, www.wcrf-uk-org), with a lifetime risk of about 1:9 and with the majority (75 per cent) of UK cases seen in men aged over 65 years. Prostate cancer is also treatable if detected early. Screening is available in the form of digital rectal examination, which can be uncomfortable and undesirable, and uptake has been found to

## ISSUES

### The impact of COVID-19 pandemic on cervical cancer screening

In Scotland, in 2019/20 for the year ending 31 March and thus prior to most of the national lockdown, uptake of cervical screening was at 71.2 per cent; with a noticeable 10 per cent difference between women in the most deprived and the least deprived areas. Data from one large health board area collected between 1 November 2019 and October 2020, encompassing eight months of the pandemic and associated lockdown and halts to service, showed that only 43 per cent of the number of pap smear tests from the previous year had been conducted (Masson, 2021). Partly this is due to the national Scottish screening services being halted between 30 March and 29 June 2020, and only resumed for urgent cases from then until routine appointments commenced again in September. Partly it is due to the consequent backlog of cases then needing to be invited. And partly it is due to people responding to symptoms differently during a pandemic and perceiving barriers to reporting them at a time when the NHS were dealing with a pandemic (see also Chapter 9 ☛). Only time will tell what the outcome of delayed screening is for cancer statistics and outcomes.

be avoided until symptoms become serious with obvious implications for treatment and survival. A less invasive method exists, Prostate Specific Antigen (PSA) testing: this involves a test to assess levels and density of a protein produced by the prostate and released into the bloodstream at a higher level following the onset of prostate cancer. However, there are wide variations in normal levels of PSA and the test suffers from a lack of **sensitivity** (it fails to detect disease in about 15 per cent of cases where it is present) and **specificity** (about two-thirds of men with an elevated PSA won't have prostate cancer, but have other conditions which also influence PSA). In fact a recent systematic review and meta-analysis of the data from five trials but amounting to a significant 721,718 men (Ilic et al., 2018) concluded that the PSA test has only a limited effect on mortality from prostate cancer over ten years to the extent of only one less death from prostate cancer per 1000 men screened. In spite of limited effect, men can access the PSA test on a case by case basis if they wish to and as long as they are given full information regarding the tests potential limitations this controversial test may continue to be offered. A qualitative study examining the influences on 20 men's uptake of PSA testing at their GPs, found however that the GP's were perceived to have struggled to provide the men with balanced information (Rai et al., 2007). High-profile campaigns, including Movember, seek to raise the profile of men's cancer and the need for screening (including self-examination), as males are generally found to have a lower uptake of health screening than women.

Further examples of screening for disease include one predominantly used among the middle-aged and one among pregnant women. The former is *bone density screening* which checks for bone deterioration and signs of osteoporosis, with screened individuals receiving a result indicating either early signs of bone disease (osteopenia) who can take action to prevent further bone loss, or osteoporosis; in both cases treatment involves increased calcium intake (daily medication in the case of osteoporosis) and increased weight-bearing exercise. At the other end of the age spectrum, *antenatal screening* procedures (amniocentesis) checks whether maternal serum alphafoetoprotein levels are indicative of spina bifida or Down's syndrome. In this instance, screening is routinely offered, at least in the UK, to pregnant women over the age of 30, and, if results are positive, there are no treatment options, but rather decisions to be made regarding continuation or termination of the pregnancy.

**sensitivity (of a test)**

the ratio of true positive tests to the total number of positive cases expressed as a percentage; for example, a sensitive test may have 95 per cent success in detecting a disease among patients known to have that disease; a test with high sensitivity has few false negatives

**specificity (of a test)**

the ratio of true negative tests to the total number of negative cases expressed as a percentage; for example, healthy people are correctly identified as not having the condition being tested for; a test with high specificity has few false positives

Where national population screening programmes exist, individuals are typically invited to screening while they generally consider themselves healthy, whereas being invited for screening on the basis of family history or age may mean that individuals already perceive themselves as being 'at risk'. As psychologists, the differences between these two groups are worthy of consideration.

In order to try to maximise the benefits of screening to both the individual and to society, criteria for effective screening programmes have been set out.

## Criteria for establishing screening programmes

Austoker (1994: 315) described several criteria on which the introduction of screening programmes aimed at early detection of prostate, ovarian and testicular cancer should be based. These criteria have been developed over time (see Holland and Stewart, 2005) and extended to consider the need for quality evidence drawn from randomised controlled trials before making screening recommendations (see the UK NHS National Screening Centre website (Public Health England, 2015) for several additional criteria). The general criteria are that:

- The condition should be an important health problem: i.e. prevalent and/or serious.
- There should be a recognisable early stage to the condition, or, in the case of screening for risk factors, clear benefit to identifying changeable risks.
- Treatment at an early stage of a detected disease should have clear benefits to the individual (e.g. reduced mortality) compared with treatment at a later stage.
- A suitable (safe and validated) test with good sensitivity and specificity should be available.

**Photo 4.3** Mammogram: a routine experience for women aged 50+

*Source*: Shutterstock.

- The test should be acceptable (clinically, socially and ethically) to the general population.
- Adequate facilities for diagnostic assessment and treatment should exist (including adequate staffing).
- Screening frequency and follow-up should be agreed.
- The individual and healthcare costs should be considered in relation to the individual and public health benefits.
- Evidence-based information regarding the potential consequences of testing, any potential further investigations or treatment, should be provided to potential participants in order to enable informed choice re undertaking screening.
- Any particular sub-groups to target should be identified.

## The costs and benefits of screening

While many screening programmes for both disease detection and risk factor status exist, questions remain as to whether the benefits to the individuals or to wider society justify the economic costs of implementing large-scale screening programmes. Furthermore there are also personal costs to be considered: there are not always clear answers to screening results, false positives may lead to inappropriate or over-treatment, and the process of screening can create significant anxiety (Ilic et al., 2013; Marteau and Kinmouth, 2002). For example, the attendance for mammography screening appears to be preceded by some anxiety, particularly where the woman considers herself to be at high risk, and in fact this anxiety can prevent future attendance (Absetz et al., 2003; Montgomery and McCrone, 2010).

Significant variation in screening uptake exists across Europe, as seen in Figure 4.3. For example in France the rate jumped from a low 29.9 per cent to a moderate 57.7 per cent, the Netherlands showed a decline to a figure of

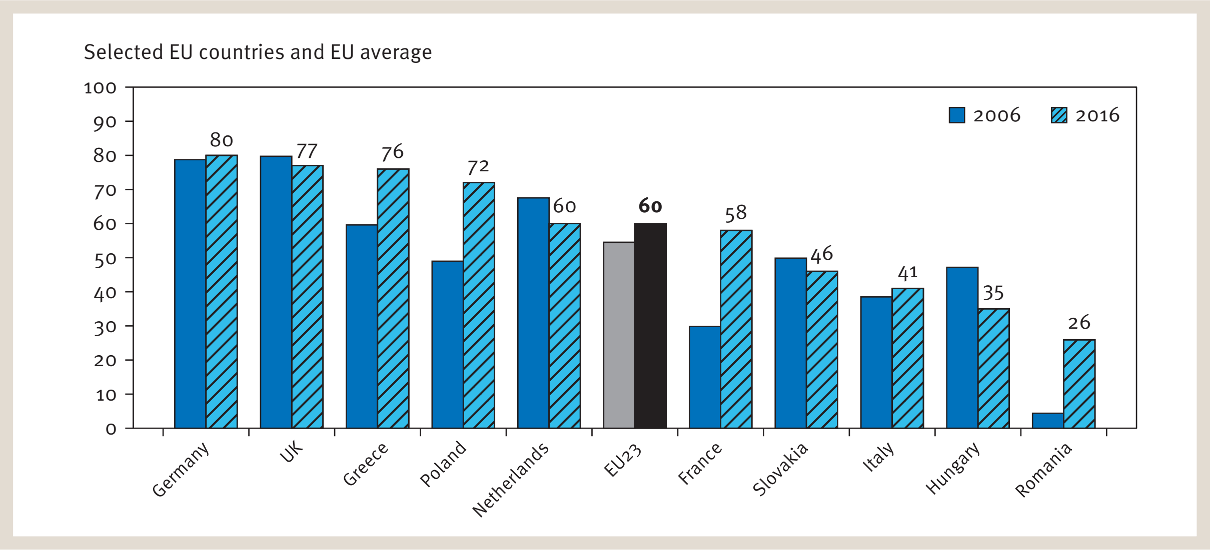

**Figure 4.3** Cervical cancer screening in women aged 20–69 in the past 3 years, around 2006 and 2016. EU countries and EU average.

Notes: The EU average is unweighted and includes countries with data overing the whole time period
*Source*: Adapted from Health at a Glance, 2018, Figure 6.16, p161).

60.3 per cent, and the UK which remained relatively stable at over 70 per cent. Overall the proportion of women screened in the EU over the decade to 2018 increased from 56 per cent to 61 per cent (OECD/EU, 2018).

It should be noted, however, that the highest rates of cervical screening uptake do not necessarily translate into greater five-year relative survival rates. For example, Austria has the highest uptake figures but their five-year survival figures are the same as the UKs at 64 per cent (OECD/EU, 2018). This raises inevitably questions of screening utility but also of the treatment availability and effectiveness variation across countries.

In the case of genetic testing, for example to identify whether an individual carries the gene that predisposes towards the development of Huntington's disease (an adult-onset disease), there is actually nothing that can be done to change the individual's risk, and therefore some question the value of screening other than as a means of preparing the individual for their future. In contrast, for those identified as carrying the BRCA1 or BRCA2 gene for breast cancer, there is an option of prophylactic surgery (i.e. breast removal) in order that disease cannot manifest itself (Lerman et al., 2000; Kauff et al., 2002). In this group there is evidence of psychological benefit including increased awareness of one's options for surveillance or prophylactic surgery and reduced uncertainty (Braithwaite et al., 2004; Lim et al., 2004). Hamilton et al. (2009) reviewed the evidence of negative psychological consequences of BRCA1 and BRCA2 testing in studies which assessed distress at various timepoints following testing and found that although distress increased initially among those given a confirmed carrier status compared to non-carriers, this returned to baseline levels over time. However other findings suggest that provision of a positive genetic risk result causes significant feelings of hopelessness about future health, which can persist for several years (Meiser, 2005; Bennett et al., 2008, 2010). Contrary to expectations, receipt of a negative test result does not inevitably reassure the individual (Bennett et al., 2008; Geirdal et al., 2005; Michie et al., 2003), possibly because the testing itself raises an issue into awareness, or because the genetic counsellor has then to explain that there may be other, unidentifiable risk factors, including as yet unknown gene carriers (Ropka et al., 2006), or other risks inherent in the individual's health behaviours or obesity, which mean that they should not consider themselves at 'no risk' whatsoever.

Family members and partners are also affected by the identification of genetic risk as they may then also need to be tested, or share the responsibility for any identified children's risk. Results, for example, from a systematic review of male partners' response to women's ovarian/breast cancer risk suggests that the process causes significant distress in the partners of women identified as mutation carriers, although this was not all due to the result itself but to wider relationship and communication factors (Sherman et al., 2010). While most people will cope with the screening process and its outcomes, for some, including those with ovarian cancer, the emotional and behavioural consequences are significant (Anderson et al., 2007).

Given the need for balance between costs and benefits of many forms of screening as described here, it was noted that the information given to those invited for screening tends be brief, emphasising the public health benefits of participation in terms of reduced morbidity and mortality, rather than perhaps addressing the potential impact on the individual (Marteau and Kinmouth, 2002 p. 78). For an individual to be fully informed prior to making a decision about screening uptake requires informing them about the possible adverse outcomes of screening and the limited prognostic benefits of some treatments (if any are available) for some individuals. This may of course affect the uptake of screening by some of those who would in fact have benefited from early detection and treatment, which creates a dilemma for screening professions who want to maximise screening uptake and public health gain.

## Making decisions about screening

Griffith et al. (2009) examined whether healthy adults formed an interest in, or intention to seek, genetic testing for breast cancer on the basis of the perceived pros and cons of such testing. Making decisions in this way is sometimes referred to as 'utility maximisation': i.e. it is assumed that a person weighs up the pros and cons of a choice and then selects the option that provides them either with the greatest perceived benefit, or, alternatively, the least undesirable consequences. To test whether or not utility maximisation occurs, this experimental study manipulated the understanding of genetic testing among 142 undergraduate students by providing information about testing in three different ways (Positive information only; Positive followed by Negative; Negative followed by Positive) compared to a control group who received information irrelevant to the genetic-testing decision questions. Beliefs about the pros and cons of testing, and the stated interest in, and likelihood of, testing were assessed pre- and post-manipulation. The experimental information in all three information groups influenced the ratio of pros to cons, and the interest in, and likelihood of, testing reported; however, there was a non-significant association between the weighted ratio of pros–cons and the post-manipulation interest and likelihood scores. This suggests that utility maximisation was *not* occurring and that models of decision-making need to look beyond simply the pros and cons of behaviour. This can be seen in the many models of behaviour and health behaviour utilised by health psychologists (see Chapter 5 ☛).

Individuals considering any form of health screening will not just approach health professionals for information, using, for example, friends and family as sources of information, or, increasingly, the internet. The use of a lay referral network is considered in Chapter 9 ☛ with regards to responses to bodily changes or symptoms. Health professionals cannot control where individuals receive health information from nor the quality of the information provided. A review of studies of online health information seekers concluded that women, the more educated and those with greater income and faster internet speeds, made more use of this source of health-related information in general, with those aged 30–44 years being most active (European Centre for Disease Prevention and Control review by Higgins et al., 2011). A WHO study of e-health trends in seven European countries and over 9,000 respondents (Andreassen et al., 2007) found that 71 per cent of internet users had used the internet for health purposes, and, more specifically, further analysis found that 29 per cent had used information from the internet to decide whether or not they needed to see a doctor (Sorensen, 2008). There is evidence of bias in e-health sources on the topic of health screening, for example a large-scale review of the nature of online information about breast cancer screening mammography found much was biased towards screening uptake, and limited clear information about the possibility of false positive and false negative results or about the adverse effects of screening, such as overdiagnosis and overtreatment was presented (Jørgensen and Gøtzsche, 2004). Few websites informed readers of the limited evidence of a reduction in risk of mortality in those screened compared with unscreened individuals (which is in fact only about 0.1 per cent reduction in relative risk of breast cancer over ten years). Overstating the benefits of screening, or understating potential risks or adverse consequences of screening results, is not providing the individual with fully informed choice.

Screening, for whatever risk factor or disease, is not compulsory. The generally low level of uptake of screening opportunities plays an important part in whether people go on to develop diseases that they may have been able to avoid or reduce their risk of developing. So far, we have described screening which involves an individual attending an appointment; however, other forms of health screening rely on an individual performing the screening themselves.

### WHAT DO YOU THINK?

What does it mean when a person has been tested for carrier status of a particular gene? Do you know? It has been found that the general public commonly do not understand the issues of heritability, recessive genes or gene penetrance. There is an obvious and growing need for education and information about these very issues as more and more genes are identified that predispose us to various diseases.

What thoughts do you have about genetic testing? Write down a list of pros and cons, for example in relation to breast or prostate cancer testing. Consider what your decision may be if testing were to become more widely available.

## Self-screening behaviour

Although self-examination behaviour is perhaps more commonly considered in relation to early detection of breast cancer, the past decade has seen growing awareness and practice of testicular self-examination (TSE) and skin self-examination. There has in fact been some controversy over the **efficacy** of breast self-examination (BSE) in saving lives, for example a large randomised trial carried out in Shanghai, China (Thomas et al., 2002),

**efficacy**
Bandura's technical term analogous to confidence

whereby BSE was either taught or not taught to a huge sample (266,064) of women factory workers aged 30+ found no effect on survival over a 10 year follow-up period of the BSE training. An identical percentage of women developed breast cancer and died in both groups (0.10 per cent). What added further to controversy about the value of BSE was that the women in the BSE-trained detected more lumps, with a larger number being found to be harmless (benign), which obviously meant that the costs of healthcare visits and biopsies for those individuals were significant but unnecessary. This and other studies are cited as informing changes in national guidelines, with BSE no longer specifically recommended in Australia (Australian Government, Cancer Australia, 2015).

Among men, testicular cancer is relatively low incidence at around 1 per cent of all male cancers, although this is doubled among those aged 30–35. Surviving testicular cancer is possible in 95–100 per cent of cases if the disease is detected early; however, over 50 per cent of cases present to health professionals after the early, more treatable, stage has passed. Men have been shown to be, less likely to engage in self-examination than women (Courtenay, 2000; Evans et al., 2005) and less willing to engage in cancer screening generally, although sharing women's beliefs in screening effectiveness (Davis et al., 2012). A recent study found that later diagnosis was associated with a range of factors including low awareness, knowledge, and confidence in performing TSE, and that regular TSE practice itself decreased the odds of a late-stage diagnosis among those who reported delaying seeking healthcare (Rovito et al., 2021). The implications of TSE for improved survival are raised by such findings and although greater prospective evidence is needed there is an obvious need for greater awareness-raising with regards to this behaviour.

Likewise, skin cancer incidence is also increasing, being the fifth most common cancer in the UK in 2017 accounting for 4 per cent of all cancers with a predicted increase over the next two decades due in part to climate changes (World Cancer Research Fund, 2021). Incidence is highest in those aged 20–40, yet early detection of skin lesions of the more harmful type (malignant melanoma) can lead to high cure rates Whether self-examination is effective in this early detection has, however, been questioned and in fact is thought not to reduce morbidity or mortality. Perhaps surprisingly, even though the incidence of skin cancer is high in Australia with the population having one of the highest lifetime risks of melanoma, no specific techniques or frequency of self-examination is in current guidelines (Australian Government, Cancer Australia 2015b).

A real challenge to health educators who seek to increase sun protection behaviours (e.g. use of sunscreen, avoidance of sunbeds) is the general perception within society that sun exposure is healthy. While in some instances this is correct and there is evidence of positive effects of sun exposure on wellbeing and mood, on vitamin D production and bone strengthening, there is a clear association between sun exposure and malignant melanoma, particularly in fair-haired, light-skinned and blue-eyed individuals. There is also some evidence of gender differences in tanning behaviours. For example, Scottish female adolescents were more likely than their male counterparts to engage in riskier behaviours and hold pro-tanning beliefs (i.e. that a tan made them feel better, healthier and more attractive), despite reporting higher awareness of skin cancer (Kyle et al., 2014). Such differences suggests that interventions should address the value placed on a particular 'risk behaviour', as this will likely affect the intervention's effectiveness (see Chapter 3 ☛ for the same point in relation to smoking).

## Uptake of screening behaviour

Psychology, particularly health and social psychology, has a large part to play in helping to identify predictors of the uptake of screening programmes, such as individual attitudes and beliefs about illness, about screening, and about preventive behaviour. (Chapter 5 ☛ considers attitudes and beliefs about behaviour more fully and Chapter 9 ☛ considers illness perceptions). While the increasing availability of screening programmes for many diseases and disease risk factors seems to have increased uptake, uptake remains at a lower level than is considered optimal in terms of disease reduction at a societal level.

## Factors associated with screening behaviour

A range of factors have been found to be associated with the non-uptake of screening opportunities or self-examination behaviour, including:

- *Demographic factors*: lower levels of education and income (the most disadvantaged groups show lower uptake typically); age and gender (e.g. younger

**Photo 4.4** Education about the risks of excessive sun exposure needs to start early

*Source*: Val Morrison.

women tend not to attend risk-factor screening; older women take part in breast cancer genetic screening); marital status and a personal or family illness history (e.g. Ropka et al., 2006)

- *Cognitive factors*: lack of knowledge about the condition or about the purpose of screening and its potential outcomes; lack of self-belief (self-efficacy, see Chapter 5 ☛) in terms of being able to practise self-examination correctly (for example in testicular self-examination (Steadman and Quine, 2004; Rovito et al., 2021).
- *Emotional factors*: embarrassment regarding the procedures involved/ body exposure; fear that 'something bad' will be detected; fear of pain or discomfort during the procedure. Fear is found among both female and male sampled. Teo et al. (2016) and Christy and colleagues (Christy et al., 2014) did not find masculinity beliefs reduced attendance at colorectal cancer screening.

Some of these factors will co-exist. For example, attendance at cervical screening among BAME women (from Indian, Pakistani, Bangladeshi, Caribbean or African background) in England was significantly lower than among White British women and was related to demographic factors of age, low educational status and language barriers, as well as low perceived risk due to a lack of understanding of screening's relevance even in the absence of symptoms or sexual activity (Marlow, Wardle and Waler, 2015). Studies of breast self-examination have found that even among women who do perform it, many do not do so correctly (i.e. it should ideally be carried out mid-menstrual cycle, in an upright position as well as when lying down, and should include examination of all tissue in the breast, nipple and underarm areas). Relatedly, Steadman and Quine (2004) demonstrated that a simple intervention, which required half of the participants to write down and visualise when, where and how they would self-examine their testes over the forthcoming three weeks, led to a significantly higher proportion of them self-examining than that found in the control group who did not form such plans. This study demonstrates the relative ease with which behaviour can be changed, although a longer-term follow-up would be beneficial to check whether self-examination practices were maintained beyond the study period. This intervention focused specifically on making an individualised plan for action, referred to in health psychology as forming an 'implementation intention'. This construct, and further research supporting its practical utility in developing interventions, is described in Chapter 5 ☛.

# Immunisation/vaccination behaviour

## The purpose of immunisation

Public health policy is to provide vaccinations that provide long-lasting protection against specific disease without adverse consequences to the individual, and with the costs of providing the vaccination being outweighed by the costs of having to treat the disease if no vaccination were to be provided. Vaccination is the oldest form of immunisation, in which immunity is provided to an individual by introducing a small amount of an **antigen** into their body (either orally, intramuscularly or intradermally (injecting into the skin)), which triggers the development of antibodies to that specific antigen. Some vaccinations, such as orally administered polio vaccine, measles, mumps and rubella, use live components, while others, such as hepatitis B use inactivated components. The main emphasis of immunisation has been on the prevention of childhood disease (with the exception perhaps of influenza vaccination to the elderly or vulnerable, or of vaccines to enable foreign travel (e.g. Hepatitis B, Yellow fever)).

All EU Member States have established child vaccination programmes which are considered to be highly cost effective; where the uptake of immunisation against infectious disease is widespread, it is beneficial to the wider community when 'herd immunity' is achieved. The UK policy with regards to child immunisation is shown in Table 4.2.

**Table 4.2** Immunisation policy in the United Kingdom*

| Age | Vaccine | Means of administration |
|---|---|---|
| 2–4 months | Polio | By mouth |
| | | Combined injection |
| | | Injection |
| 12–15 months | Measles, mumps and rubella (MMR) | Combined injection |
| 3–5 years | Polio | By mouth |
| | | Combined injection |
| | Measles, mumps and rubella (MMR) | Combined injection |
| 10–14 years | Rubella (girls) | Injection |
| 12–13 years | HPV (girls) | Two injections over 6–24 months |
| 15–18 years | Tetanus booster | Injection |

*HPV: Human Papilloma Virus

At least in developed countries over the past century, vaccinations against infectious disease, particularly childhood diseases, have been credited with the virtual eradication of diseases that in previous centuries caused widespread morbidity and mortality, such as smallpox, diptheria and polio (e.g. Woolf, 1996). High hopes of achieving population immunity against measles (with a target vaccination prevalence in excess of 95 per cent) following the introduction of a vaccine in 1988, have not quite been achieved. Initially uptake was high (97 per cent), however in part due to a now fully discredited 1998 study that reported adverse effects of the combined MMR vaccination, there was a downturn in immunisation uptake, to an average 81 per cent in 2004. Things have recovered somewhat with the 2018 figure being 89 per cent across Europe in terms of those having received at least one dose, where many countries exceed the desired 95 per cent level (e.g. Belgium. Germany, Portugal, Spain, Greece and others), although others do not as yet (e.g. UK, France, Italy, Netherlands) (ECDC, European Centre for Disease Prevention and Control, 2018).

However, in developing countries, immunisation coverage is variable leading to concern that some diseases, such as whooping cough, tuberculosis (TB) and measles, may re-emerge. While childhood illnesses such as measles do not feature highly in death statistics, TB still appears in the 'top ten' causes of death in low income countries in 2019 (WHO, 2020).

More recently, infection with **human-papillomavirus (HPV)** has been identified in 70–95 per cent of cervical cancers (Kuper et al., 2000; OECD, 2012) and although causality is only suggested in a small percentage of cases a vaccine was developed in 2006. Clinical trials found the

**antigen**
unique process found on the surface of a pathogen that enables the immune system to recognise that pathogen as a foreign substance and therefore produce antibodies to fight it; vaccinations introduce specially prepared viruses or bacteria into a body, and these have antigens

**human papillomavirus (HPV)**
a family of over 100 viruses, of which 30 types can cause genital warts and be transmitted by sexual contact; while most genital HPV come and go over the course of a few years, two specific HPV types markedly elevate the risk for cancer of the cervix

vaccine to be effective in both adults and children, with 90 per cent effectiveness in those who have not already acquired infection (Lo, 2006, 2007; Steinbrook, 2006). Since 2008 many countries including the UK have offered an HPV vaccination programme in secondary schools as part of the NHS childhood vaccination programme. Targeted initially at girls aged 12–13 years, on the basis that the vaccination needs to be given before sexual activity commences. a ‘catch-up’ programme in 2009/10 targeted 15–17-year-olds. In 2014, the original vaccine was replaced with one which also protects against genital warts (Gardasil) and which is believed to provide protection for at least 20 years. Vaccination is now offered in most European countries for girls aged 9–13 years as recommended by the WHO (WHO, 2018c), and involves two injections given at least six months apart. Parental permission is required in order for the vaccination to be given, which has been controversial given the implicit acknowledgement of sexual activity.

Since 2020, the world has seen a major programme of vaccination moving from development through testing and medicine authority approvals, to *mass* rollout (at least in the developed world) of a vaccine against the coronavirus SARS-CoV-2, that causes COVID-19. Declared a pandemic by the WHO on the 11 March 2020, the global scientific response has been impressive. Never before has a vaccination, of which there are varying types with varying programmes of delivery (NHS England, 2020), had so much publicity, so much investment within a relatively short period of time and so much ‘lay’ debate to balance with expert advice. Compulsory administration of any vaccine has generally not been supported (Blume, 2006) and in the absence of this there is a need for clear and consistent messaging if uptake is to be optimal (Rieger, 2020) (see ‘In the spotlight’ for a discussion of vaccine uptake hesitancy). At the time of writing in the UK there is a likelihood that we will move to compulsory COVID vaccinations for those working in care homes.

While socio-economic variables such as low educational attainment have sometimes been found to influence the uptake of vaccination (see Chapter 2 ☛), not all studies report this (Lamden and Gemmell, 2008). Evidence more consistently points to emotional and cognitive predictors of uptake:. Risk perceptions and outcome expectancies and the research evidence as to their utility in explaining health behaviour are examined in Chapter 5 ☛.

**Photo 4.5** Immunisation behaviour is crucial to public health, yet is influenced by many cultural, social, emotional and cognitive factors. Here, a queue of mothers take up the first opportunity of vaccination for their child against measles to be offered in their village

*Source*: Getty Images/Jacob Silberberg.

## IN THE SPOTLIGHT

### COVID-19 and vaccination hesitancy

It is unlikely that many readers of this textbook will not have been invited formally or encouraged informally to attend a local vaccination centre over the past year or so. The current vaccination delivery figures across Europe are variable. Figures to 1 July 2021 record 60.6 per cent of EU/EEA residing adults to have had at least one vaccine, and 38.9 per cent to have had both (where two are required). National variations exist, for example 83.5 per cent and 59.7 per cent respectively in the UK (UK government dashboard, to 23 June 2021) compared to 66.8 and 44.3 per cent respectively in Ireland, in Norway 56.6 and 33.0 per cent respectively, and in Slovakia, 43.2 and 32.6 per cent respectively (https://vaccinetracker.ecdc.europa.eu/public/extensions/COVID-19/vaccine-tracker.html#uptake-tab)

Vaccine delivery figures hides those who did not take up the offer or opportunity to be vaccinated when offered i.e. the figures reflect those who so far have been vaccinated. Most EU countries have rolled out vaccination to the elderly and physically vulnerable and uptake there has been good (e.g. ONS, 2021). However within these data is evidence of lower uptake of first vaccination among those of Black African or Black Caribbean origin, and among those vaccinated and going onto a second vaccine, uptake was lowest among those of Bangladeshi and Pakistani origin. As roll-out moved into younger, and to all intents and purpose healthier sectors of the population, significant worry is being expressed about those who are not taking up the vaccine opportunity. Laine, Cotton and Moyer (2021) note in the American context where there were many who were uncertain and hesitant about being vaccinated (estimated to about half of the American population, Fisher et al., 2020) that there is not a simple dichotomy of those that want vaccinated and whose who do not. Some are simply unsure. Why are people hesitant about taking up the opportunity for a free vaccination given the evidence of significant efficacy in preventing contracting or carrying COVID-19 or becoming seriously ill if infected? Laine points to issues around trust of those advocating vaccination, of the vaccine itself, and to understanding of the benefits and risks of being vaccinated compared to the benefits and risks of not being.

Closer to home, a recent study examining influences on COVID-19 vaccine hesitancy as compared to acceptance or actual resistance has been conducted among 1079 UK and Irish adults during the 2020 vaccine roll-out (Walsh et al., 2021) . Informed by earlier UK and Irish findings regarding wider sociodemographic influences on uptake behaviours (e.g. self-interest, trust in authorities, religious beliefs, conspiracy, and paranoid beliefs, as well as differences in thinking styles and personality traits) (Murphy et al., 2021), Walsh's study adds in a range of attitudinal and belief variables informed by sociocognitive models of health behaviour theories (see Health Belief Model and Theory of Planned Behaviour, Chapter 5 ☛), and critically measures of 'civic responsibility' (i.e. addressing the participants consideration of the welfare of those around them and their moral responsibility towards their external environment). This has been a topic of prominence in discussions around mask-wearing and social distancing in the COVID pandemic and moves us away from questions of self-protection to that of protecting others. This is an extremely important addition.

Although this study addresses 'intention' to be vaccinated in response to the question 'If the NHS/HSE advised you to take an available COVID-19 vaccine would you comply?', with respondents having the choice of three response *yes* (vaccine accepting), *no* (vaccine resistant), and *unsure* (vaccine hesitant), the findings still point usefully to the complexity of influences that play a role. The majority of the sample in both countries intended to accept vaccination (75 per cent overall, 79 per cent Ireland, 71 per cent UK), an important minority (14 per cent overall, 13.6 per cent Ireland, UK per cent) were unsure and said no (11 per cent overall, 9.6 per cent Ireland, UK). Significant differences were found in variables distinguishing the groups and here I highlight only factors that distinguished the ‘yes’ respondents from the ‘unsured’ as the ‘unsures’ offer perhaps greater intervention opportunity than the ‘refusers’.

In Ireland, the ‘unsures ‘ had less positive attitudes to vaccination (although had higher perceived severity regarding infection with COVID-19), were more likely to be female, less likely to have positive peer influences regarding vaccine uptake, and reported less civic responsibility. In the UK sample, the ‘unsures’ were disproportionately represented by BAME groups, had lower positive peer influence, and were less likely to be influenced by their GP. They also perceived higher vaccine risk and less benefit, and perversely, higher reported adherence to public health guidance. When the samples are combined, the factors distinguishing ‘unsures’ from the ‘yes’ respondents were being female, having lower vaccinations attitudes, less regard for civic responsibility, lower positive peer influence, greater perceived vaccine risk, and perceived severity of COVID. The ‘yes’ group in comparison were more likely to be influenced by governmental advice than the ‘unsures’.

The novelty of the studies above is that they look beyond vaccine behaviours themselves to wider beliefs, such as in civic responsibility, or trust of authority figures. Other factors also likely play a role, for example, differing perceptions of the illness itself. For example, in relation to childhood conditions meningitis is almost universally feared, whereas measles, or flu/influenza may be considered a less serious illness. With regards to COVID-19 infection, early evidence and resulting media attention stressed a higher risk to the elderly or physically vulnerable, which likely affected risk perceptions of the young and healthy. Beliefs about the illness itself need to be positioned along with balancing both evidence-based and false information about vaccination risk, concern about vaccine safety, speed of development etc. In fact mRNA vaccine technology had been studied for almost 20 years, thus was in existence and able to develop to the specific coronavirus at speed with no loss of scientific rigour. Managing people’s anxieties and also their expectancies of the benefits of being vaccinated (will they be able to discard masks, move physically closer to people, travel abroad?) has become a challenge to our policy makers and those who communicate their policies. Concerns need to be addressed through education rather than dismissed. Lay perceptions of risks attached to the virus or to vaccinations need to be addressed through informed and balanced communication, placing risks in the contexts of other risks many people take virtually daily ie smoking, taking the contraceptive pill, travelling in a motor vehicle). Public health messaging needs to be seen to be informed, relevant (to the young, the old, the vulnerable, the healthy, to BAME groups as well as majority groups), and credible.

What the immunisation debates we have all likely witnessed and experienced since spring 2020 do is highlight is the power of the media. While it is important that the media stimulate debate, it is important that they do so objectively and in an evidence-based manner. Health professionals also, in communicating with their patients, need to present both sides of the evidence so as to enable informed decisions.

## Things to think about and research yourself

What informed your choices about whether or not to have the COVID vaccine? Do you think that you would provide your child(ren) in the future with (any) vaccination protection, for example against measles, HPV? Would you consider all vaccines as equally important or would you weigh up the pros and cons for each one independently? Where can people find reliable evidence of the pros and cons of immunisation?

Where do policy makers and public health speakers go ‘wrong’ in communicating the individual and public health benefits of immunisation? Do you think they, and also health professionals could do better in communicating the benefits of immunisation, and if so how?

## SUMMARY

This chapter has provided an overview of a range of behaviour often described as ‘behavioural immunogens’: behaviour that acts in ways that protect or enhance an individual’s health status. The evidence as to the associations between a healthy diet, being physically active, adhering to any necessary medications or treatments and taking preventive measures with regards to screening or immunisation uptake is clear. In addition, a lack or low level of ‘immunogens’ is health damaging, as seen, for example, in the contribution of low levels of physical activity to the global obesity figures which in turn carries its own health consequences (see Chapter 3 ☛). Given the convincing evidence of a behaviour–disease association reviewed in this and the previous chapter, we could perhaps be forgiven for expecting that the majority of people would behave in a manner that protects their health. However, we have shown that this is not borne out by statistics. It is increasingly evident that there is a complexity of influences on health behaviour practices and so this is what we turn to next. Chapter 5 ☛ will describe the key psychosocial theories and models of health behaviour employed in health psychology research.

## Further reading

Kardas, P., Lewek, P. and Matyjaszczyk, M. (2013). Determinants of patient adherence: A review of systematic reviews. Frontiers in Pharmacology, DOI: https://doi.org/10.3389/fphar.2013.00091

A useful review which informed a multinational study of adherence to medication among those with hypertension – I was thrilled to be part of the UK team on this. https://digital.nhs.uk/pubs/hse2018

The Health Survey for England website provide regular updates on their surveys. For example, this one in 2018 interviewed 8,178 adults aged 16 and over, and 2,072 children aged 0 to 15, and presents data relevant to several of the chapters in this textbook: Overweight and obesity in adults and children; Asthma; Adults’ health-related behaviours; Adults’ health; Longstanding conditions; Children’s health; Social care for older adults

Biddle, S.J.H. and Mutrie, N. (2008). Psychology of Physical Activity: Determinants, Wellbeing and Interventions, 2nd edn. London: Routledge.

Although a bit dated now, this book still provides useful coverage of the influences on, and benefits of, physical activity

Visit the website at **go.pearson.com/uk/he/resources** for additional resources to help you with your study.

# Chapter 5

# Explaining health behaviour

## Learning outcomes

By the end of this chapter, you should understand and be able to describe:

- how demographic, social, cognitive and motivational factors influence the uptake of health or risk behaviour
- key psychosocial models of health behaviour and health behaviour change
- how 'continuum' or 'static' models differ from 'stage' models in terms of how they consider behaviour change processes
- the research evidence that supports or refutes the models in terms of which factors are predictive of health behaviour and health behaviour change

# COVID-19 and handwashing: Behavioural strategies for reducing COVID-19 transmission in the general population

In 2020 the pandemic Coronavirus worked its way across the world and brought with it a need for hand hygiene like many had never experienced before. How well did you wash your hands typically before this? Did you even think about washing your hands before and after going to your local supermarket? Evidence drawn from previous epidemics (e.g. swine flu in 2009) suggests that many did not. In this chapter it will become clear that having knowledge about what is required to protect, maintain or promote health is an insufficient motivator of behaviour. Being informed about a health risk does not necessarily mean that human beings, complex human beings, will act in a manner which reduces their personal risk- or furthermore, the risk their behaviours carry for others. In a BMJ opinion blog, published on the very day that UK government issued their coronavirus action plan, Michie and colleagues (Michie, West and Amlott, 2020) outline ways to reduce the knowledge-action gap. The factors involved in shifting us from ‘knowing’ to ‘doing’ are many, ranging from contextual and social factors to individual norms and resources (skills, knowledge, capability) and personal motivations. Effective handwashing needs the resource of water or hand sanitiser, it needs knowledge of how best to do it (possibly singing Happy Birthday twice as you work fingers separately and then interlink all fingers in a smooth rubbing movement, not forgetting the back!) as well as when to do so (after touching surfaces, pets or others), and it needs the person to ‘want’ to do it, either for their own sake or for that of others-they need to perceive a value in doing so. Complex although this may seem, as with everything, practice makes perfect, and also sets down a new habit. Do you still wash your hands more carefully that you did pre March 2020? If so, good. If not, ponder why not?

This chapter will address many aspects of health behaviour change, the barriers as well as the facilitators. In this and subsequent chapters we will show that the influences on human behaviour are many and that they can differ within and across individuals and behaviours. Such complexity does not however make behaviour change impossible!

## Chapter outline

The previous two chapters have described behaviour that is associated with health and illness: positive or health-protective behaviours such as exercise and health screening, and health-risk behaviours, such as smoking or unsafe sex. This chapter aims to describe the key theoretical models that have been proposed and tested in terms of their ability to explain and predict why people engage in such behaviour. Personality, emotions, beliefs and attitudes play an important role in motivating our behaviour, as do our goals and intentions, social circumstances and social norms. The key psychological models and their components are described and critiqued, drawing on evidence from studies of an array of health behaviours. While our understanding of health behaviour remains incomplete due to the complexity of influences upon human behaviour generally, the empirical studies described have identified many significant and modifiable influences that offer potential targets for future health promotion and health education, as described in Chapters 6 and 7 ☛.

## Distal influences on health behaviour

One way of considering the factors predictive of health behaviour generally is to view some influences as 'distal', such as culture, environment, ethnicity, socio-economic status, age, gender and personality, and others as 'proximal' in their influence, such as specific beliefs and attitudes towards health-risk and health-protective behaviour. This division is somewhat arbitrary but is intended to reflect the fact that some distal influences, such as socio-economic status, operate on behaviour indirectly, by means of their effects on other more proximal factors, such as a person's attitudes, beliefs or goals. These proximal factors therefore potentially **mediate** the effect of socio-economic status on health. To illustrate this further, there is reasonably consistent evidence that people in the lower socio-economic groups drink more, smoke more, exercise less and eat less healthy diets than those in the higher socio-economic groups (e.g. Clare et al., 2014). Evidence of such a distal influence does not, however, explain 'how' or 'why' this is the case, (see Chapter 2 ☛ for a full discussion of socio-economic inequalities in health). Further explanation can be offered from evidence showing that social class affects health beliefs (see Chapter 1 ☛), which in turn may then affect behaviour. These health beliefs can be considered 'closer' to the behaviour (more proximal) and offer a more feasible target for intervention than would an intervention aimed at altering a person's social class. Beliefs may therefore mediate the effects of more distal influences, and this hypothesis can be tested statistically.

Another term you may come across when reading about relationships between variables is **moderation**. Moderating variables explain the conditions under

**mediate/mediator**

mediating variables explain how or why a relationship exists between two other variables: for example, the effects of age upon behaviour may be mediated by health beliefs; thus age effects would be said to be indirect, rather than direct

**moderator/moderation**

moderating variables explain the conditions under which a relationship between two other variables may exist: for example, the relationship between individual beliefs and behaviour may be different depending on gender or health status which a relationship exists, for example the relationship between a potential predictor (such as social class) and an outcome (for example screening uptake) may vary according to categories of another variable (e.g. male/female, under 65/over 66). The models described in this chapter all acknowledge the role of these 'distal' influences, but vary in the extent to which they hypothesise or test specific associations between these and the more proximal factors. Before turning to the models, we therefore present some of the evidence regarding the specific distal influences of demographic characteristics of age, gender and personality.

## Demographic influences

In terms of age, the health behaviours that receive the majority of attention from educational, medical and public health specialists (i.e. smoking, alcohol consumption, unprotected sexual activity, exercise and diet) are patterns of behaviour set down in childhood or early adulthood. For instance, the majority of smokers take up the habit as teenagers, often attributed to the finding that attitudes also change at this time when adolescents generally begin to seek autonomy (independence) from their parents. This may include making health-related decisions for themselves: for example, whether or not to start smoking or drinking alcohol, whether or not to brush their teeth before bed. Influences on decisional processes, attitudes and behaviour change during these years, with more credence being given to the attitudes, beliefs, values and behaviour of one's peers (and in fact siblings) than to the advice or attitudes of parents or teachers (e.g. Mercken et al., 2011). In fact we all tend to listen to messages from others when they are congruent with our pre-existing beliefs.

While establishing a sense of identity among one's peer group and attempting to 'fit in', it is perhaps not surprising that, for some adolescents, this will include the initiation of 'risk' behaviour if this is part of the peer group norm and thought likely to be positively received or beneficial (in the short term at least) (Mitchell, Schoel and Stevens, 2008; Reniers et al., 2016). Gender has been shown to influence the nature and performance of health-protective or health-risk behaviours, as we have described in the two preceding chapters, and it is likely that perceptions of health and health behaviours, and perceptions of risk, and the meanings attached to those offer a partial explanation for gender differences in health behaviour. For example, in Renier and colleagues (2016) study, males perceived behaviour as less risky, took more risks, were less sensitive to negative outcomes (present or future outcomes) and were less socially anxious than the female participants. Perhaps these differences relate to projections of masculinity and a desire to be seen as 'strong', as suggested with regards to drinking alcohol excessively (Visser and Smith, 2007), or avoiding seeking health care which is an issue in older men as well as in adolescents (Calisanti et al., 2013; Marcell et al., 2007). Conversely, constructions of masculinity may also contribute to health-enhancing activity or health protective activity, such as exercise. For example, Visser and Smith's (2007) qualitative study of males aged 18–21, illustrates linkages made between health-risk behaviour and social constructions of masculinity, with some material highlighting how factors, such as sporting success, can 'compensate' for the reduced perceived masculinity attributed to an individual who drinks less:

> . . . really icons of masculinity who go out and booze, and get in fights, and get lots of women and stuff like that, they are regarded as . . . the prime kind of, you know, specimens of maleness . . . (but) because I was better than most of the players, they didn't, like, pressure me into drinking, because . . . you know, it was kind of like I could say to them 'Forget it' or whatever. Um . . . that was, that's personally me, but then I have friends who . . . weren't quite as experienced as me at hockey, but just to kind of get into the group I think they felt the need to partake in that [drinking].

In this study exceptions to the masculinity and drinking behaviour association were seen among some Black and Asian Muslim interviewees whose religion exerted stronger influences on their behaviour than did the need to be seen as 'masculine'. Rochelle (2019) points out that conceptions of masculinity, which tend to emphasise strength, independence and power (which may encourage males to engage in health risk behaviour (Courtenay, 2011) have typically been derived from White, westernised samples, and thus not representative of other ethnicities or cultures. This was confirmed in Rochelle's survey of 495 men living in Hong Kong (Hong Kong Chinese, mainland Chinese, Caucasian and South Asian). In this culture, Chinese men 'demonstrate submission in the context of filial piety or hierarchy' (e.g. to parents) and are 'valued for both their brains and physical strength', but emphasis is also given to 'men's dominance over women, with great importance placed on patriarchy'

(p. 161). Health-promoting behaviours (exercise, good diet, low substance use etc.) were associated with younger age and conformity to masculinity norms in all sub groups apart from the South Asian men. This contradicts typical findings from western samples. Positive effects of masculinity norms exist, probably because different, multifaceted constructions of masculinity exist and culture influences these constructions. In addition gendered constructions are also changing over time.

The broader influences of age, gender and ethnicity need to be acknowledged to a greater extent than is often the case in studies of health behaviour and health behaviour change. Individuals operate in varying social worlds, each with their own systems and norms, which exert influence on individual beliefs and behaviours. We try to highlight these wider influences wherever possible, including in Chapter 2 ☛. Also, as noted in Chapter 3 ☛, health-risk behaviours can cluster, with the majority of individuals engaging in more than one health-risk behaviour. Age was found to play a role in typifying the clusters in a study of a representative UK adult sample (Birch et al., 2019) where males aged 18–24 years from more deprived groups consumed the most ready meals and fast food, whereas older men (65 years+) were more likely to consume harmful levels of alcohol, and older women were more likely to be sedentary.

Another influence on behaviour that is not consistently operationalised or examined in studies of health behaviour change (although usually included in diagrammatic representation of the models), is that of personality.

## Personality

Personality is, generally speaking, what makes individuals different from one another. Each of us thinks and behaves in a characteristic manner, showing traits that are particularly enduring regardless of situation. Different scientists have proposed different numbers of key traits or dimensions of personality; two of the major examples are presented here.

### Eysenck's three-factor model

According to Eysenck (1970, 1991), individual personality is reflected in an individual's scores along three dimensions:

1. *Extroversion* (outgoing social nature): dimensionally opposite to introversion (shy, solitary nature).
2. *Neuroticism* (anxious, worried, guilt-ridden nature): dimensionally opposite to emotional stability (relaxed, contented nature).
3. *Psychoticism* (egocentric, aggressive, antisocial nature): dimensionally opposite to self-control (kind, considerate, obedient nature).

For example, one individual may score positively and high on neuroticism and extroversion but negatively on psychoticism, whereas another may score positively and high on neuroticism, and negatively and high on extroversion and psychoticism. These three factors have received significant empirical support and are considered to be valid and robust personality factors (Kline, 1993). However, another model exists, often referred to as the 'big five' (McCrae and Costa, 1987, 1990), which identifies five primary dimensions of personality — and, within health psychology, it is this model which has received the most attention (see also Chapter 12 ☛ for more detailed discussion of personality and responses to stress).

### McCrae and Costa's five-factor model

The Big Five traits include:

1. neuroticism
2. extroversion
3. openness (to experience)
4. agreeableness
5. conscientiousness.

Validated in different cultures and at different points in the lifespan (McCrae et al., 2000, 2010), these traits are considered relatively stable and enduring. Many associations between these personality traits, mental health and illness have been reported (Smith and Parkhurst, 2018; Mezquita et al., 2019) with research increasingly addressing the mechanisms through which these associations may operate. Generally speaking high extroversion, neuroticism or openness increases risk-taking behaviour (e.g. Hampson, Vollrath and Juliusson, 2015; Magee, Heaven and Miller, 2013). For example, neuroticism and extraversion were both associated with external eating in adults (Keller and Siegrist, 2015), and among a large sample of Norwegian children, neuroticism was associated with both emotional overeating and emotional undereating, whereas agreeableness was associated with the converse (Vollrath, Torgersen and Torgersen, 2018). In contrast, better health outcomes are seen among conscientious individuals (Smith and Parkhurst, 2018), attributed to findings that those scoring higher in conscientiousness (and agreeableness) engage in less risk-taking (e.g. Nicholson et al., 2005) and to findings that conscientiousness is generally associated with health-protective behaviour or indeed clusters of behaviours (Joyner, Rhodes and Loprinzi, 2018; Joyner and Loprinzi, 2018).

As indicated above, neuroticism has tended to associate with health risk behaviour, however in the prospective data of Joyner et al. (2018) no association was found. In explaining this, the authors suggest that in fact neurotics may avoid potentially harmful situations as a consequence of their characteristic anxiety and self-consciousness. This fits with findings that neuroticism has been associated with greater health-care use – avoiding potential negative outcomes (illness) may explain why highly neurotic individuals tend to report greater attention to bodily sensations and to label them as a potential threat or 'symptom' of disease more than people lower in neuroticism (see Chapter 9 ☛). However, Friedman (2003) noted that inconsistent findings around the effects of neuroticism likely points to the existence of 'healthy neurotics' as well as 'unhealthy neurotics' and generally speaking personality traits offer insufficient, partial, explanations for health or risk behaviour.

Another commonly investigated aspect of personality is generalised **locus of control** (LoC) beliefs (Rotter, 1966). Rotter originally considered individuals to have either an internal LoC orientation (i.e. they place responsibility for outcomes on themselves and consider that their actions affect outcomes) or an external orientation, which suggests that they place responsibility for outcomes at the door of external factors such as luck, fate, other people. A sense of internal control was thought to be adaptive but research was needed to establish why this might be the case (i.e. do individuals who believe they have control behave or cope with stress differently, for example?) (see Steptoe and Poole, 2016 for a review and also Chapter 11 ☛).

Testing this assumption in relation to health outcomes, Kenneth Wallston and colleagues (Wallston et al., 1978) developed the MHLC (multidimensional **health locus of control**) scale, an LoC scale specific to health beliefs, with three statistically independent dimensions:

1. *Internal*: an individual with strong internal beliefs considers themselves as the prime determinant of their health state. Theoretically associated with high levels of health-protective behaviour and with Bandura's self-efficacy construct (see below) for example, a person starting a healthy eating programme,
2. *External/chance*: an individual with strong external beliefs considers that external forces such as luck, fate or chance determines their health state, rather than their own behaviour.
3. *Powerful others*: an individual with strong beliefs on this scale would consider their health state to be determined by the actions of powerful others such as health and medical professionals, for example going to a local health clinic to request appetite suppression medication. Powerful others beliefs can, however, detract from an individual taking active responsibility for behaviour, with such individuals being overreliant on a medical 'fix'.

Reflecting the theoretical underpinning to locus of control, that of social learning or social cognitive theory (Bandura, 1986) whereby an individual acts on the expectancy of certain valued outcomes, Wallston argued that the MHLC dimensions become relevant only if an individual values their health. If individuals do not value their health, it is thought that they are unlikely to engage in health-protective behaviour (even if they believe in personal control over health), whereas they hypothesised that individuals with an internal, or powerful others HLC who do value their health would be more likely to behave in a health-protective manner (Wallston and Smith, 1994). However a large scale analysis of data pertaining to ten different health behaviours in over 7,000 students recruited from 18 European countries did not confirm this (Steptoe and Wardle, 2001) and the relationships between control constructs and behaviour did not change when health value was considered.

**locus of control**

a personality trait thought to distinguish between those who attribute responsibility for events to themselves (i.e. internal LoC) or to external factors (external LoC)

**health locus of control**

the perception that one's health is under personal control; controlled by powerful others such as health professionals; or under the control of external factors such as fate or luck

Such generalised LoC dimensions, also proved to be only modest predictors of behaviour, with relationships differing depending on the behaviours addressed. Overall in Steptoe and Wardle's analysis referred to above, the odds of healthy behaviour was increased by 40 per cent among those high in internal HLOC compared to those low in internal HLOC, and reduced by 20 per cent in those high in chance HLOC compared to low in chance LOC.

As a result of modest findings attributed to generalised constructs, some researchers turned their attention to behaviourally specific and proximal constructs, such as **perceived behavioural control** (see theory of planned behaviour on and **self-efficacy** and the health action process approach model in Chapter 5 ☛). For example, beliefs in low personal control over the cure of skin cancer were associated with higher perceived risk/likelihood of developing skin cancer but lower intention to engage in prevention (Cameron, 2008). She suggested that this may reflect underlying personality such as **dispositional pessimism** or anxiety, as other studies have found these to influence susceptibility beliefs (e.g. Gerend et al., 2004).

Armitage (2003) suggested that dispositional or generic control beliefs might in fact influence these more specific proximal control beliefs, based on his findings that the ability of specific perceived behavioural control beliefs to explain intention was strongest among those individuals with high generalised internal LoC. More recently researchers have demonstrated associations between **trait self-control** (i.e. the ability to resist temptation and override impulsive or immediately rewarding behaviour with control which is more effortful and goal-oriented) (de Ridder et al., 2012) and avoiding a range of health-relevant temptations such as alcohol or snacks or taking up health behaviours such as physical activity or healthy eating (Hankonen et al., 2014; Hagger, Gucciardi, Turrell and Hamilton, 2019).

Taken together, while traits or generalised beliefs by definition may be less amenable to change than the cognitive, emotional or even social factors more typically examined by health psychology research, such findings suggest that interventions targeting those exhibiting broad traits that increase the risk of unhealthy behaviour could usefully address behavioural skills (see Chapter 7 ☛).

Overall, findings highlighted in this section support suggestions that more distal characteristics may affect proximal predictors of behaviour and that the personality–health behaviour relationship warrants consideration (O'Connor, 2014).

## Self-determination theory

What may add to the predictive utility of personality factors is some exploration of how personality traits effect the motivations for carrying out behaviour. Motivation is a component of most models of health behaviour discussed in this chapter, but is central to **self-determination theory** (Deci and Ryan, 2000) where intrinsic and extrinsic motivation are distinquished. Intrinsic motivation relates to where a person is motivated to behave in a certain way for the inherent personal satisfaction or rewards it produces, such as feelings of increased competence, autonomy, or relatedness to others. In contrast, extrinsically motivated behaviour arises from perceived externally situated rewards, such as a need for peer approval and are more controlled or constrained motives compared to autonomous intrinsic motives. Supporting this theory, Ingledew and Ferguson (2007) found that students scoring high on agreeableness or conscientiousness had intrinsic, autonomous or self-determined motivations to perform safer sex (e.g. 'Personally, I would practise safe sex because. . . I personally believe it is the best thing for my health'), rather than extrinsic, external or controlled motivations (e.g. 'Personally, I would practise safe sex because. . . I feel pressure from others').

Further evidence of a relationship between personality and behavioural motives is provided in a study of

| | |
|---|---|
| perceived behavioural control | one's belief in personal control over a certain specific action or behaviour |
| self-efficacy | the belief that one can perform particular behaviour in a given set of circumstances |
| dispositional pessimism | having a generally negative outlook on life and a tendency to anticipate negative outcomes (as opposed to dispositional optimism) |
| trait self-control | the general ability to resist temptation and suppress impulse |
| self-determination theory | this theory considers the extent to which behaviour is self-motivated (i.e. by intrinsic factors) and influenced by the core needs of autonomy, competence and psychological relatedness |

extreme sport athletes in Turkey (Ceylan, Altiparmak and Akcakoyun, 2016). In this study, no gender differences were found in terms of motives for engaging in a range of extreme sports, however amongst males extroversion was higher and associated with the motive of exercising to let off stress. These findings also bring to attention the importance of affect and stress reduction motives. The role played by emotion in health behaviour is discussed below (these are often neglected in our studies of health behaviour, see West and Brown, 2013 with regards to addictive behaviours).

## Social influences

Humans are fundamentally social beings. Our behaviour is a result of many influences: the general culture and environment into which we are born; the day-to-day micro-culture in which we live and work which generally has a set of shared norms and expectations; the groups, sub-groups and individuals with whom we interact; and our own personal emotions, beliefs, values and attitudes, all of which are influenced by these wider factors. We learn from our own positive and negative experiences, but we also learn 'vicariously' through exposure to, and observation of, other people's expectancies, behaviour and experiences. The behaviour of other people in our culture or smaller social groups creates a perceived 'social norm', which suggests implicit (or explicit) approval for certain behaviours, values and beliefs (Aronson et al., 2005). For example, a four-year follow-up study of nearly 10,000 American high school students (Choi et al., 2003) found clear differences in the factors that explained initiation to smoking from non-smoking, and progression from experimental (defined as irregular, social, short-term) smoking to current smoking. Those who initiated smoking were typically white rebellious students who did not like school, and who perceived greater parental approval for smoking. Those who progressed in their smoking behaviour perceived peer approval for their smoking and perceived experimental smoking as safe. College and university students similarly have been found to make assumptions about what constitutes 'typical' alcohol intake, and thus, for some, their problematic drinking can be judged as 'normal' when it may not be (Perkins et al., 2005). These assumptions of what relevant others 'do' have been described as 'descriptive norms', and differ from norms which 'proscribe' how others want you to behave in a certain situation, which have been referred to as 'injunctive norms' (Stok et al., 2014, and see 'Issues' later in this chapter where we show that both types of norms may influence behaviour but in different ways).

In relation to health-risk behaviour, broader social influence is seen in the many sources of information that a person is exposed to: for example, televised advertisements graphically illustrating the negative consequences of smoking; an older sibling or parent appearing to be healthy in spite of regular binge-drinking episodes; a classroom workshop on how to 'just say no' to the first offer of a cigarette or other drug; a friend who uses amphetamine claiming it helps them study. There is consistent evidence to show that the credibility, similarity to self and even the attractiveness of the source of information influences whether or not attitudinal change or behaviour change occurs as a consequence (e.g. Dijkstra and Ballast, 2012; Petty, Barden and Wheeler, 2009), including when interventions are delivered online (Webb et al., 2010 and see Chapter 6 ☛). Evidence also exists that we may explore a message more when it is advocated by a majority as opposed to by a minority, even when the recommendation is against our own self-interest (Martin and Hewstone, 2003). However, as we discuss below, changed attitude is only part of the story!

## Goals and self-regulation of behaviour

Health-protective and risk behaviours are generally performed for a reason; people have **outcome expectancies** attached to them as described in **social cognition theory** (SCT) and thus much behaviour tends to be consciously goal-directed (both short- and long-term goals) (e.g. Carver and Scheier 1998). Health behaviour serves coping functions (which may be considered as short-term goals of the behaviour): for example, for some individuals smoking may serve the function of giving a time-out

outcome expectancies

the outcome that is expected to result from behaviour, e.g. exercise will make me fitter

social cognition theory

a model of social knowledge and behaviour that highlights the explanatory role of cognitive factors (e.g. beliefs and attitudes)

**Photo 5.1** Social norms have been found to be important predictors of whether or not a person initiates specific health behaviours, in this instance smoking and drinking alcohol

*Source*: Ansgar Photography/Corbis/Getty Images.

from stress, for others it may aid avoidance of snacks. The implication therefore is that interventions designed to reduce ‘unhealthy’ behaviour need to take account of the coping functions or goals that individual behaviour serves for each individual – it is these goals that will motivate the behaviour (see also Chapter 6 ☛).

Processes of **self-regulation**, the cognitive and behavioural processes by which individuals guide, control, modify or adapt his or her responses, enable an individual to achieve desired outcomes or reduce undesired outcomes, i.e. their goals. Goals focus our attention and direct our efforts. More valued, and more specific, goals lead to greater and more persistent effort than general ‘do your best’ goals (Locke and Latham, 2002, 2004). Goal-setting is closely related to behaviour-change techniques advocated by Abraham and Michie (2008), with setting SMART (specific, measurable, attainable, realistic and timely) goals a core component (see Chapter 6 ☛).

self-regulation

the process by which individuals monitor and adjust their behaviour, thoughts and emotions in order to maintain a balance or a sense of normal function

Cognitive regulation (i.e. controlling or modifying our thoughts) is required as well as emotion regulation (controlling or modifying our emotions) if we are to successfully organise and execute goal-directed activity: in other words, if we are to turn our intentions into actions (Mann et al., 2013). An inability to control thoughts and evaluate decision options and potential outcomes or to regulate our emotions (for example, when drunk!) may increase impulsivity and risk-taking behaviour (Magar et al., 2008). There is some suggestion that women use such self-regulation more than men: for example, in relation to planning for exercise uptake (Hankonen et al., 2010) and healthy eating (Renner et al., 2008).

## Attentional control

Cognitive regulation by definition requires the management of one’s thoughts and this has attentional implications. Attentional control is defined as the extent to which a person can focus on activities and goals and avoid being distracted by competing goals, demands, or negative arising emotions (such as anxiety about failure) that might interfere with goal attainment or, at least, be able to return to goal-directed activity after the distraction has passed or been dealt with (e.g. Luszczynska et al., 2004). Attentional control is different from action control which refers to self-regulation of behaviour, i.e. action

(Sniehotta et al., 2005), As a behaviour change technique (Chapter 6 ☛), encouraging attentional control could translate into statements such as ‘If you feel the urge to smoke, focus your attention on other things happening around you – not on your desire for a cigarette’.

Thinking more broadly about our goal-directed behaviour, existential theory (Frankl, 1946/2006) states that individuals need to be able to find meaning in their lives if they are to achieve mental health or even happiness (Diener and Seligman, 2002; Diener et al., 2009). A sense of meaning or purpose in life is derived from achieving one’s wants and goals and feeling that one’s activities are worthwhile. Having a weak sense of meaning or purpose in life has been associated with greater likelihood of risk behaviours such as smoking (Konkolÿ Thege et al., 2009) and drinking alcohol (Marsh et al., 2003).

All of this section relates to conscious processes, and the models we present throughout this chapter do likewise. However we also are guided by non-conscious motives, perhaps driven by **implicit** emotions such as positive uplifts in mood experienced during performance of certain behaviours (such as during exercise). Van Capellen and colleagues (van Cappellen et al., 2018) have recently proposed the ‘upward spiral theory of lifestyle change’ which considers the role of positive affect and implicit motives in relation to health behaviour change, perhaps particularly relevant to the maintenance of behaviour change, as previously highlighted in Chapter 4 ☛ in relation to exercise (Rhodes and Kates, 2015). Positive affect and enjoyment may be necessary conditions for behaviour change maintenance – for example setting exercise goals that are meaningful and desirable, as well as choosing an exercise that is enjoyable, may make change more achievable and maintainable. Intervention mapping approaches could consider such factors more fully than currently (see also Chapter 6 ☛).

Another factor to consider is that health behaviours co-occur and can be be inter-connected, such as drinking alcohol and smoking or being inactive (Hagger-Johnson et al., 2013; Birch et al., 2018; Nudelman, Kalish and Shiloh, 2019). One behaviour may lead a person to carry out other behaviours that are considered congruent with the first (Fleig et al., 2014, 2015) and which fit with a person’s self-identity of being a ‘healthy’ or an ‘unhealthy’ person perhaps (see PRIME theory below).

The next part of the chapter addresses a range of psychological theories and models that have been developed in an attempt to explain and thereby predict health behaviour.

### WHAT DO YOU THINK?

Think of three aspects of your life that are important to you and that you currently value highly. Why do you value them? What meaning do they have? What function do they serve?

What goals do you hope to achieve over the next six months? Over the next five years?

Now think about your own health or risk behaviour. Do your behaviours ‘fit’ with your current values? Do they fit with your short- and long-term goals?

Finally, think ahead to when you reach middle age (or if you have already reached this, think of your post-retirement years!). Do you think your behaviour, goals or values will have changed? If so, in what way and why?

## Models of health behaviour

First, it is important to remind the reader that by adopting healthy habits, we are only reducing the statistical risks of ill health, not guaranteeing that we will lead a long, healthy life. Furthermore, examining human behaviour and the motives for it will never provide a full explanation for the huge variations in people’s health. This is true for two broad reasons. Firstly, behaviour is not the only factor that causes disease. Secondly, humans, and the influence upon them, are inconsistent. For example:

- Different health behaviours are controlled by different external factors: for example, smoking may be socially discouraged, while exercise may be supported; however, cigarettes are still readily available, whereas access to exercise facilities may be limited.
- Attitudes towards health behaviours vary within (as well as between) individuals. In the same individual, alcohol consumption may be viewed positively whereas the use of cannabis, or exercising, may be viewed negatively
- Motivating factors may differ for different health behaviours for example, the same person may smoke to relax, exercise to lose weight and consume alcohol to socialise

- Motivating factors may change over time: for example, adolescents may drink alcohol as a form of rebellion but later may consider it an aid to social interaction.
- Individual differences in attitudes and motivations are in part explained by life stage and the associated perceived norms: for example, a teenager may diet for appearance reasons, while a middle-aged man may diet to reduce his perceived risk of having a heart attack.
- The social context can trigger or alternatively limit behaviour: for example, alcohol consumption may be lower when with parents or colleagues than when drinking with friends.

Given those caveats, we can only ever hope to offer a partial explanation of behaviour and associated health consequences to those seeking to develop interventions to prevent or reduce negative consequences.

Early theories as to why we changed our behaviour were based on the simplistic, implicit assumption that:

Information → Attitude change → Behaviour change

These were found to be naive. Although many past, and even some current, health education campaigns draw upon this simplistic premise, the evidence regarding predictors of behaviour change show that things are much more complex. Eccles and colleagues (2012) conducted an important comparison of this implicit model of behavioural prediction with other theory-led models (Social Cognition Theory, the Theory of Planned Behaviour, Learning Theory, the Precaution Adoption Process Model, and Implementation Intentions), which we consider in this chapter, and the Common Sense Model of Illness (see Chapter 9 ☛). The implicit model performed poorly in relation to the performance of 5 healthcare professional behaviours. Within patient or general public populations it has also been shown that simply having information or knowledge, for example about the value of a low-cholesterol diet or the health risks of sun-tanning behaviour (see Chapters 3 and 4 ☛), is not inevitably associated with healthy attitudes towards the behaviour. For example, Kyle's study of more than 2,000 Scottish adolescents (Kyle et al., 2014) found that although more females than males knew that sun exposure was associated with skin cancer risk, they also held more positive attitudes towards tanning behaviour, and sunbathed more often. More than information and knowledge about a health threat is required to motivate behaviour change. Attitudes and risk perceptions do, however, play a significant role, as you will see in the models presented below.

## Attitudes

What is an attitude? Attitudes are the common-sense representations that individuals hold in relation to objects, people and events and reflect what they think, and how they feel and plan to act in relation to that person, object or event (Eagly and Chaiken, 1993). While earlier theorists had proposed attitude as a unitary affective evaluation (i.e. you either like something/someone or you do not; e.g. Thurstone, 1928); and others presented a two-component cognitive and evaluative model (e.g. Allport, 1935), this three-component model of attitude has gained acceptance, whereby attitudes are considered as relatively enduring, generalisable and consisting of three related parts:

1. *Cognitive*: beliefs about the attitude-object – for example, exercising is a good way to relieve stress; exercising is expensive.
2. *Emotional*: feelings towards the attitude-object – for example, exercising is embarrassing/fun.
3. *Behavioural* (or intentional): intended action towards the attitude-object – for example, I am/am not going to exercise.

The three components of attitudes were considered to be generally consistent with each other and likely to predict behaviour. However, the empirical evidence to support a direct association between attitudes and behaviour is inconclusive. Even if attitudes become more negative towards a health-risk behaviour, increased perceived personal risk and behaviour change may not follow. This may be because an individual can hold several different, sometimes conflicting, attitudes towards a particular attitude-object, depending on social context and many other factors. I may, for example, enjoy the taste of chocolate but be worried about the implications of high fat/high calorie intake. I may hold a positive attitude towards eating and drinking healthily, but an even more positive attitude towards socialising with friends. Such contradictory thoughts can produce what is known as **cognitive dissonance**, which many people will attempt to resolve by bringing their thoughts into line with one another. However, others maintain a dissociation between attitudes and behaviour: for example, so-called dissonant drinkers, who continue to drink with friends more than they would prefer to despite holding a number of negative attitudes towards the behaviour. This conflict is also sometimes referred to as **ambivalence**, where a person's motivation to change could potentially be undermined by the holding of ambivalent attitudes or competing goals (e.g. Sparks et al., 2001).

### Measuring attitudes

It has been noted that measuring explicit, stated, attitudes can lead to a **social desirability bias**, i.e. people may falsely report having negative attitudes towards behaviours they perform butwhich they know are held in negative esteem socially, for example, illicit drug use or, increasingly, smoking? Technological developments in reaction time testing enables measurement of **implicit attitudes** (Fishbein and Ajzen, 2010) as seen in social and cognitive psychology. For example, by experimental presentation of images of different faces or body genders or colours, or different food types, the speed with which individuals can categorise these computer-presented images according to attitudinal criteria such as 'good/bad' 'attractive/not attractive', tasty/not tasty', etc., is considered to reflect a person's implicit attitudes. One advantage of implicit attitudes is that they are considered less prone to social desirability bias, but, because they are not under our conscious control, they may associate with impulsive behavior and also be harder to change (Fazio and Olson, 2003; Strack and Deutsch, 2004). Evidence suggests that implicit attitudes might complement a person's motivation to behave in a certain way. For example Oliver and Kemps (2018) experimental study found that motivational processes (autonomous and controlled motivations) and implicit processes (including attitudinal and attentional bias) were independently associated with incidental physical activity (house or garden work, general activity at work or at leisure). It is unclear as yet whether implicit processes offer opportunities for interventions, although behavioral interventions using 'nudge principles' are thought to have potential for both implicit and motivational processes (see Chapter 6 ☛).

**cognitive dissonance**

Where a person holds thoughts that are inconsistent with each other and which causes discomfort that a person may try to resolve through seeking information in support of one belief, or by ignoring or changing one's belief/ attitude

**ambivalence**

the simultaneous existence of mixed thoughts and feelings towards an attitude object, person or event i.e. simultaneously holding, both positive and negative evaluations

**social desirability bias**

the tendency to answer questions about oneself or one's behaviour in a way that is thought likely to meet with social (or interviewer) approval

**implicit attitude**

attitudes that activate unintentionally in response to actual or symbolic presence of an attitude-object (stimulus) and which therefore don't require the cognitive effort of explicit attitudes

Many factors can shape, challenge or change implicit beliefs or more explicit attitudes, cause them to be ignored, or increase the likelihood of them being acted upon. One important influence is that of personal relevance and perceived risk.

## Risk perceptions and unrealistic optimism

People often engage in risky or unhealthy behaviour because they do not consider themselves to be at risk from its consequences, likely due to limited understanding or limited acceptance of any threat information received (Wright, 2010). Threat information (e.g. the health risks of smoking) is not necessarily understood nor systematically and rationally processed. In fact there is evidence that such information, which is often presented alongside vivid and potentially distressing images, can trigger defensive and avoidance responses that reduce the likelihood of behaviour change (Good and Abraham, 2007; van't Riet and Ruiter, 2013), and that we may instead prefer to attend to information that affirms our sense of self or which is favourable (Sharot and Garrett, 2017).

For some, their risk perceptions may be based on comparisons with others, rather than with objective indicators of risk. For example, believing, for example, that 'I do not smoke as much as "person X" and therefore won't be at risk of cancer compared with them' may lead to inaccurate risk estimates. Weinstein (1984) named this biased risk perception, which he found to be common, **unrealistic optimism**. He noted that individuals engage in forms of social comparison that reflect best on themselves (comparative optimism/optimistic bias) (Weinstein, 2003) and that the negative behaviour of peers is focused on more when making these judgements than is the same peers' positive health behaviour. Such selective attention can lead to unrealistically positive appraisals regarding personal risk.

Weinstein (1987) identified four factors associated with unrealistic optimism:

1. a lack of personal experience with the behaviour or problem concerned;
2. a belief that their individual actions can prevent the problem (e.g. behavioural control);
3. the belief that if the problem has not emerged already, it is unlikely to do so in the future: for example, 'I have smoked for years and my health is fine, so why would it change now?';
4. the belief that the problem is rare: for example, 'Cancer is quite rare compared with how common smoking is, so it is pretty unlikely I'll develop it'.

Over subsequent decades unrealistic optimism has been considered as one of a range of irrational false beliefs that may influence behaviour (e.g. Jefferson, Bortolotti and Kuzmanovic, 2017). There is some evidence that unrealistic optimism is associated with greater belief in control over events (e.g. 'I am at less risk than others because I know when to stop drinking'), and that control beliefs are associated with risk-reducing behaviour. Others however suggest that the relationship between unrealistic optimism and behaviour is likely to be negative because individuals underestimate their actual risk and thus while this may reduce the distress of accepting risk, it prevents them taking precautions against the risk occurrence. Research testing the consequences of unrealistic optimism would require measuring actual risk as well as perceived risk, otherwise it is hard to state whether a person is actually 'unrealistically optimistic' or not! (Shepperd, Klein, Waters and Weinstein, 2013). Some authors (see Flanagan, 2009) suggest that the expression of unrealistic optimism may not even reflect genuine illusory belief, but more an expression of hope, which may actually prompt positive behavior. This raises questions when considering the data presented in empirical studies- do the data reflect the presence of unrealistic/illusory beliefs or of hopes and desires and does this impact on the extent to which we succeed in predicting behaviour? (Flanagan, 2009).

**unrealistic optimism**
also known as 'optimistic bias', whereby a person considers themselves as being less likely than comparable others to develop an illness or experience a negative event

Another issue to consider is that risk perceptions are generally defined and assessed as individually generated cognitions, i.e. the extent to which a person considers themselves as facing potential harm, (see, for example, the health belief model below), but risk perceptions are also influenced by the social and cultural context of the respondent. For example, if I were to perceive my risk of contracting TB (tuberculosis) as high while living in North Wales, this would likely be considered as being unrealistically pessimistic, however if I work with homeless populations where TB is still present, or make regular trips to countries where the incidence is high, then my beliefs may be quite realistic (for evidence of 'realistic pessimism' in a malaria endemic country, see Morrison et al., 1999). The mass media is also a primary source of information about health and associated behaviours and risks, whether it uses the scientific evidence appropriately or not. Assessing the 'realism' of beliefs against objective evidence, and assessing the context in which such beliefs arise, wax and wane is important if interventions to change beliefs are to have optimal effect.

In addition, low perceived risk is something often attached to children, particularly adolescents as the uptake of risk behavours tend to increase in adolescence and decrease towards adulthood. Steinberg (2008) proposes a social neuroscience explanation for this, attributing greater impulsivity and risk-taking *not* to the commonly sought explanations of peer pressure and evaluative differences, but to neurobiological changes in the brains dopaminergic reward systems during puberty. The combination of the biological, the psychological and the social is beginning to further our understanding of risk taking behaviour and social neuroscience is an exciting field in this context.

## Self-efficacy

As Bandura, founding father of social cognitive theory (see below) (1997: 24) states: 'It is because people see outcomes as contingent on the adequacy of their performance, and care about those outcomes, that they rely on efficacy beliefs in deciding which course of action to pursue and how long to pursue it'. Self-efficacy is defined as 'beliefs about whether one can produce certain actions' (Bandura, 1997: 29). For example, believing that a future action (e.g. weight loss) is within your capabilities is likely to generate other cognitive and emotional activity, such as the setting of high personal goals (losing a stone rather than half a stone), positive outcome expectancies and reduced anxiety about failure. These cognitions and emotions in turn affect actions, such as dietary change and exercise, in order to achieve the goal. Efficacy beliefs also promote perseverance. Success in reaching a goal feeds back in a self-regulatory manner to enhance a person's sense of self-efficacy and their further efforts to attain goals. In situations where one's own competence is unrelated or less closely tied to outcome, for example, time taken to recover from a virus, self-efficacy, as with other control constructs, is likely to be less predictive of outcome.

Self-efficacy beliefs often emerge as an important and strong predictor of individual health behaviour (e.g. predicting medication adherence in nine European countries, see Morrison et al., 2015), and behaviour change (Eccles et al., 2012), although it is not sufficient alone. Its effects are moderated by the desired outcomes – the outcome expectancies (personal, physical, social), goals and how they are valued (French, 2013).

While not all influences on health behaviour are psychological, health and social psychologists have developed theoretical models to examine which factors combine empirically to explain a wide range of behaviour. The models typically applied to behaviour change (initiation, maintenance or cessation) are presented below.

# Sociocognitive models of behaviour change

Social cognition broadly refers to how people encode, process, interpret, remember, learn from and use information in social interactions in order to make sense of the behaviour of others or of their world. Social cognition shapes our judgements (including prejudices and stereotypes), attitudes and responses, and derives from expectancy-value principles to shape our behaviour.

## Social Cognitive Theory (SCT)

According to Bandura (1977, 1986) behaviour is determined by three types of individual expectancies:

- *situation-outcomes expectancies* whereby a person connects a situation to an outcome: for example, smoking to heart attack;
- *outcome expectancies*: for example, believing that stopping smoking would reduce the risk of heart attack;
- *self-efficacy beliefs*: for example, the extent to which the person believes they can stop smoking.

SCT proposes that these expectancies may or may not provide lasting incentives to change: for example, if the outcome of changing one's diet is weight loss and weight loss is valued, then this may incentivise behaviour change maintenance; however, if weight remains the same, behaviour change may be undermined. Success or failure influences such beliefs, as do other facilitators and barriers to behaviour change, including social support and environmental factors.

Defined further by Maddux (2009) as 'what I believe I can do with my skills under certain conditions' (p. 336), self-efficacy beliefs are incorporated into several of the core models of behaviour described below. Bandura highlights interventions based on providing mastery experiences, or modelling of successes (Chapter 6 and 7 ☛) to enhance self-efficacy.

## The health belief model

One early and well known known model of health behaviour change is the health belief model (HBM) (Rosenstock, 1974; Becker, 1974; Becker and Rosenstock, 1984).

The HBM is predominantly derived from **subjective expected utility theory** (i.e. individuals are active and generally rational decision makers who are influenced by the perceived utility (usefulness to them) of certain actions or behaviour (cf. Edwards, 1954)). The HBM proposes that the *likelihood* that a person will engage in particular health behaviour depends on demographic factors (e.g. social class, gender, age), and upon four beliefs (perceived severity, perceived susceptibility, perceived benefits, perceived barriers) that may arise following a particular internal or external cue to action (see Figure 5.1). Health motivation was added in 1977. Although personal control beliefs were not explicitly theorised as part of the initial HBM model, a lack of perceived control would have been considered as a possible barrier. The concept of self-efficacy (related to personal control) was added in 1988, but not clearly theorised in relation to the other HBM components, for example does self-efficacy moderate the influence of perceived threat on behavior for example? Self-efficacy has rarely been included in studies using the HBM (Carpenter, 2010).

**subjective expected utility (SEU) theory**

a decision-making model where an individual evaluates the expected utility (cf. desirability) of certain actions and their outcomes and selects the action with the highest SEU

Specific examples best illustrate how the various components fit together:

- Perception of threat:
  - I believe that coronary heart disease (CHD) is a serious illness contributed to by being overweight: *perceived severity*.
  - I believe that I am overweight: *perceived susceptibility*.
- Behavioural evaluation:
  - If I lose weight, my health will improve*: perceived benefits* (of change).
  - Changing my cooking and eating habits when I also have a family to feed will be difficult, and possibly more expensive*: perceived barr*iers (to change).
- Cues to action:
  - That recent television programme about the health risks of obesity worried me (*external*).
  - I always feel breathless when I climb stairs, so maybe I should lose some weight (*internal*).
- Health motivation:
  - It is important to me to maintain my health.

## The HBM and behaviour

The HBM has been applied to a wide range of behaviour over many years, including engaging in health preventative behaviours such as eating a healthy diet, being physically active, and reducing or ceasing engagement in

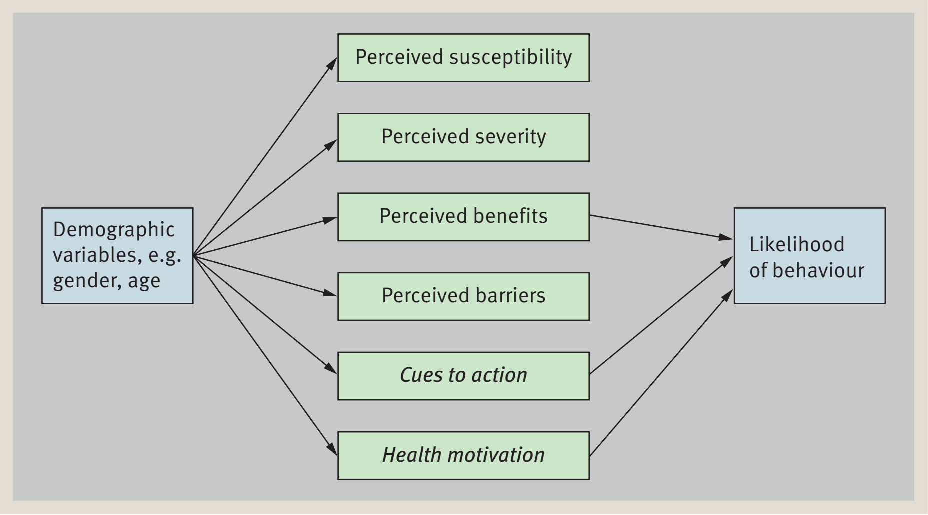

**Figure 5.1** The health belief model

unhealthy or risk behaviours, for example stopping smoking. The HBM predicts that health preventative behaviour would likely result from beliefs of susceptibility to serious health threats, and beliefs that the perceived benefits of the health behaviour outweigh the perceived barriers to that behaviour or the benefits of *not* performing the behavior in question. Conversely, with regards to reducing risk behaviour such as smoking, or increasing condom use to avoid HIV infection, the HBM would hypothesise that positive behaviour change would occur when the perceived benefits of change outweigh the perceived benefits of continued risk-taking. In addition, being motivated by health gain will increase the likelihood of that behaviour as will, as recognised in the HBM but not in the other models, an internal or external cue to action.

Many studies of behaviour have been carried out based on the HBM. Taking the example of breast self-examination (BSE), there is evidence that many people do not do it at all and that it decreases with age, even though the incidence of breast cancer increases with age. When exploring why this may be the case using the HBM, perceiving benefits of self-examination and few barriers to its performance are most consistently and most highly correlated with both intention to perform BSE and actual behaviour. Perceived seriousness of breast cancer, perceived susceptibility and being motivated towards health (e.g. seeking health information and generally engaging in health-promoting activity) were also found to be predictive (e.g. Ashton et al., 2001). This supports the need to assess health motivation rather than assume that all people are equally motivated to pursue it, as they play a small, but significant role (Abraham and Sheeran, 2007). For example, while parents are likely to be universally motivated to achieve health for their child, this alone may be insufficient when it comes to making decisions about vaccinations, with evidence that other factors such as perceived side-effects and having a poor relationship with the health-care practitioner influence uptake of vaccinations (Smith et al., 2017 and see Chapter 4 ☛).

Perceiving barriers is generally associated with low levels of preventive behaviour, for example with low levels of medication adherence among those with hypertension, (Holmes et al., 2014), or limited perceived access to facilities and low activity levels (Learmonth and Motl, 2016). The reverse has also been demonstrated, for example low perceived barriers were associated with more frequent breast self-examination (Norman and Brain, 2005) However, removing barriers is not always sufficient to increase behaviour as shown by Rhodes and colleagues (Rhodes et al., 2017) who reviewed interventions targeting adult and youth physical activity levels and found limited evidence of the effectiveness of interventions which offered environmental change. Relatedly, a lifestyle intervention which reduced perceived barriers to exercise among older couples with hypertension did not influence exercise initiation or maintenance (Burke et al. 2007). In spite of such findings, removing access barriers to leisure facilities in order to increase physical activity has been highlighted in various public health/ community initiatives (Rhodes et al., 2017).

Reviews of the overall contribution of HBM components point to their having moderate success in explaining behaviour (Abraham and Sheeran, 2007) with perceived benefits and barriers typically emerging as having a stronger relationship to behaviour (Carpenter, 2010), although this seems to vary depending on the behaviour being considered.

## Limitations of HBM

### How are the HBM components operationalised, assessed and analysed?

The model consists of several components, typically examined independently with more limited examination of the interrelationships between them. The original authors did not specify variable ordering, nor how the different variables interact with one another or combine to influence behaviour (Champion and Skinner, 2008).

Initially it was implied that components could usefully be summed (Rosenstock, 1966), but Becker et al. (1977) subsequently suggested that perceived benefits were weighted against perceived barriers, but did not specify how this was to be calculated - should the number of barriers be subtracted from the number of benefits reported, or vice versa? Do all benefits and barriers carry equal weight to the individual? Probably not.

Strecher and Rosenstock (1997) suggested that adding or even multiplying susceptibility X severity scores to get an overall ‘perceived threat’ score may enable greater prediction than using each independently and that cues to action and perceived benefits and barriers may better predict behaviour in situations where perceived threat is high.

Few of these issues have been addressed empirically, although more recently Jones et al. (2015) examined the direct and indirect effects of HBM components on flu vaccination behaviour and found that relationships were complex; specifically, exposure to a flu vaccination campaign (cue to action) affected behaviour via the mediation of perceived threat and barriers, which were in turn moderated by self-efficacy. More analyses of this type are needed.

### Are all HBM components important?

There is evidence that the HBM may overestimate the role of 'threat'. Perceived susceptibility inconsistently predicts health behaviour change and in fact health promotion messages should not overuse fear arousal as this can be counter-productive to behaviour change (Albarracín et al., 2005) (see also Chapter 6 ☛), particularly among those who lack the resource to change (e.g. Ruiter and Kok, 2006). Furthermore, studies of adolescent sexual risk-taking have pointed out that perceptions of threat or susceptibility to STDs, pregnancies, or even HIV infection are often counter-intuitive, and that behavior, such as condom use, is more strongly influenced by subjective norms see TPB below) than by HBM components (Boone and Lefkowitz, 2004; O'Dwyer, Dune, Bidewell and Laimputtong, 2018).

The question of the personal salience of different benefits and barriers to an individual is not addressed in the HBM, yet it has been suggested that highly salient beliefs (i.e. those of high importance to the individual) may predict outcomes better than a model which employs modal beliefs (Steadman et al., 2002). The salience of different factors to individuals and their influence on behaviour may also vary in different contexts, including in different populations. For example, an American study (Chen et al., 2007) found that the uptake of an influenza vaccination was strongly related to beliefs in influenza seriousness and personal susceptibility in the whole sample, but that these factors were much more strongly associated among African American and European American adults than among Hispanic Americans who were more influenced by perceived barriers to vaccination. Studies adopting the HBM often take limited account of cultural or social influences or the contexts in which behaviour occurs.

At a more micro-level, behaviours also take place in *different contexts*, for example, there is more than one person present when considering condom use and thus interpersonal dynamics and negotiation of a behavior should be considered. Evidence of the utility of the HBM here is limited. This relates to the aforementioned point that the initial HBM failed to explicitly consider whether the individual feels able to initiate the required behaviour

Telling the public Covid-19 is out of control is wrong approach

Fear is a dangerous ingredient when it comes to public health campaigns

Wed, Feb 02, 2021, 01:35

Jessie Brown

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**Photo 5.2** The use of fear messaging can be counterproductive to behaviour change

*Source*: Brian Lawless/PA Images/Alamy Stock Photo.

or behaviour change. Low *perceived control* or lack of self-efficacy were considered along with other barrier components, rather than given a central role, as seen in the Theory of Planned Behaviour (TPB) and the Health Action Process Approach (HAPA) – see below.

One factor influencing influencing control beliefs, yet often not considered is *past behaviour* – an important predictor of what we do in the future is what we have done in the past. Past behaviour has increasingly been assessed in studies in this field, where earlier studies did not assess this, and it is consistently found to be predictive, not only in relation to safer sexual behaviour (Yzer et al., 2001), but also, breast self-examination (Norman and Brain, 2005), or objective and self-report physical activity (Plotnikoff et al., 2014). The process through which past success or failure operates on future behaviour is via its effects on self-efficacy beliefs for future attempts.

Also neglected is the possible role played by *emotion*. As noted by Kiviniemi and colleagues (Kiviniemi et al., 2018, p. 99) 'much of the early foundational work on determinants of health behavior had a strongly cognitive focus . . . [but] . . . over the past 10–15 years, scientists have increasingly recognized the importance of affect in understanding health behaviour'. A person is likely to adopt the required behaviour where they believe it will reduce a perceived and feared health threat (following a cue- although this has not been examined sufficiently) *and* they believe they can carry out the required behavior *and* also that their affect/mood will influence these factors and their effects. Negative affect, for example, was found to be inversely associated with exercise behaviour among women with breast cancer (Perna et al., 2008). Kiviniemi's paper sets out a strong case for examining the interplay between cognition and affect, and indeed concepts that have emerged more recently, such as *anticipatory regret*- see below, addresses an affect-laden cognitive process.

*Enjoyment* is also a factor – as van Caappellen and colleagues (2018, p. 78) point out, drawing from some of Kiviniemi's own empirical work: 'Generally speaking, when people associate enjoyment with the thought of engaging in a health behavior, they are more likely both to intend to engage in that behavior, and to actually engage in it.' They go on to provide many examples of this in relation to physical activity, where positive anticipatory states, as well as mood enhancements during exercise, are factors associated with maintained PA.

Finally, HBM components are perhaps more relevant to predicting the initiation of positive health preventive behaviours, such as one-off screening uptake (e.g. Rawl, Menon, Burless and Breslau, 2012) than maintaining behaviour change (Rothman et al., 2009; Phillips et al., 2016).

The HBM is a static model, suggesting that beliefs occur simultaneously. This does not allow for the examination of dynamic processes such as changing or oscillating beliefs over time. Longitudinal prospective evidence is needed to inform effective and appropriately timed interventions, and therefore interventions often draw from other models in addition to the HBM. In spite of half a century of studies employing the HBM there are still gaps in our understanding of how all the components work together, and given the consistent finding that studies using the HBM components account for a relatively small proportion of variance in behaviour change; attention has turned to other, more extensive models.

## The theory of planned behaviour

The Theory of Reasoned Action (TRA) and its successor which we address here, the Theory of Planned Behaviour (TPB), originate in social psychology and derive from social cognition theory (SCT, described earlier). These assume that any social behaviour is determined by a person's beliefs about behaviour in that social context and by their social perceptions and outcome expectations.

Underlying the development of the TPB was the assumption (Fishbein, 1967; Ajzen and Fishbein, 1970) that individuals behave in a goal-directed manner and that the implications of their actions (outcome expectations) are weighed up in a *reasoned* (not necessarily rational) manner, before a person decides whether to engage in the behaviour or not (Fishbein and Ajzen, 2010).

The TPB addresses the psychological processes linking attitude and behaviour by incorporating wider social influences and perceived norms, beliefs in personal behavioural control, and the necessity of intention formation. Behaviour is thought to be proximally (closely) determined by intention, which in turn is influenced by a person's attitude towards the object behaviour (outcome expectancy beliefs) and their perception of social norms and pressures regarding the behaviour (known as a **subjective norm**) (see Figure 5.2). The extent to which they wish to comply or fall into line with the preferences or norms of others is known as motivation to comply. Behaviour change tends to occur in contexts where social support is important (Greaves et al., 2011). Research rarely addresses the *type* of influence that social networks exert at different times in life and in different relationship types, in terms of their social influence and action control (persuasive and encouraging, versus, critical and undermining, for example) (Rook et al., 2011; Sorkin et al., 2014). We address interpersonal influences further in the 'Research focus'.

The TPB components are illustrated below:

- Attitude towards the behaviour: 'Smoking is bad for my health'
    - Including outcome expectancies. *positive outcome expectancy*: 'If I stop smoking, exercising will become easier for me'; *negative outcome expectancy*: 'If I stop smoking, I will perhaps gain weight'; and *outcome value*: 'It is important for me to be healthier'
    - Perceived subjective norm: 'My friends and parents do not smoke and really want me to stop smoking'
    - Including motivation to comply: 'I would like to please my parents and friends'
- Perceived behavioural control: 'It is up to me to stop smoking and I believe I can'
    - Intention: 'I am going to stop smoking'

**subjective norm**

a person's beliefs regarding whether important others (referents) would think that they should or should not carry out a particular action; an index of social pressure, weighted generally by the individual's motivation to comply with the wishes of others

The model states that the importance of the person's attitudes towards the behaviour is weighted against the subjective norm beliefs, thus a person holding a negative attitude towards behaviour change ('I don't really like dieting') may still develop a positive intention to change in situations where their subjective norm promotes dieting and they wish to comply with their significant others (e.g. 'All my friends eat more healthily than I do, and I would like to be more like them').

The third influence on intention is that of perceived behavioural control (PBC) (Ajzen 1985, 1991), defined as a person's belief that they have control over their own behaviour in certain situations, even when facing particular barriers (e.g. 'I believe it will be possible for me to breastfeed even if I go to the supermarket café'). The model proposes that PBC will directly influence intention and thus, indirectly, behaviour. A direct relationship between PBC and behaviour is also considered possible if perceptions of control were accurate, meaning that if a person believes that they have control over their diet and actually do, then behaviour change is likely, but if the preparation of food is in fact under someone else's control, behavioural change is less likely even if a positive intention had been formed (Rutter and Quine, 2002: 12).

As with the HBM beliefs, PBC beliefs are influenced by many factors including past behaviour in relation to

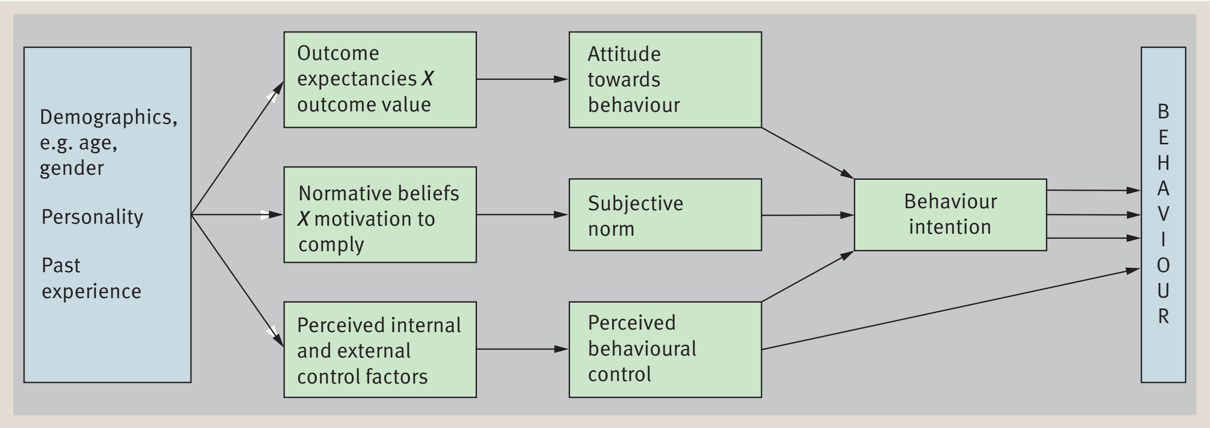

**Figure 5.2** The theory of planned behaviour

the behaviour in question, and therefore the PBC construct is very similar to self-efficacy. For example, a person who has never tried to stop smoking before may have lower PBC beliefs than a person who has succeeded in stopping previously and who may believe that it is within their control to do so again.

Most studies using the TPB report significant correlations between PBC and intention, although intention remains a stronger predictor of subsequent behaviour than PBC is directly (McEachan, Conner, Taylor and Lawton, 2011). PBC may be most powerful when it is considered in interaction with the other components of the model, such as attitudes and motivations and even more dispositional measures of locus of control. To illustrate this, Armitage (2003) found that generalised internal control beliefs independently predicted the relationship between perceived behavioural control and intention. In other words, the ability of perceived behavioural control beliefs to explain intention was strongest among individuals with high generalised internal LoC. Such findings suggest that interventions aiming to enhance specific perceived behavioural control beliefs may work better if targeted at those with a more state-like, dispositional, internal locus of control (see Chapters 6, 7 and 18 ☛).

However it is not all about PBC. In a systematic review and meta-analysis of 38 studies of predictors of sun-protection intentions and behaviour (Sutton and White, 2016), PBC and subjective norms proved significant but attitudes were the strongest predictors of intentions and intentions were stronger than PBC in terms of predicting behaviour. Intentions do not fully explain behaviour however, as seen in a systematic review of 237 independent prospective tests of the TPB, where only 19.3 per cent of the variability in health behaviour was accounted for, albeit with intention he strongest predictor (McEachan, Conner, Taylor and Lawton, 2011) however this is much weaker prediction of behaviour than previously described (Sutton, 2004). However intention is typically considered to be the proximal determinant of behaviour, reflecting both an individual's motivation to behave in a certain manner and how hard they are prepared to try to carry out that behaviour (Ajzen, 1991: 199). The TPB therefore adds to explanations offered by the HBM, which simply stated that a combination of motivational beliefs predicted a greater or lesser likelihood of action, without a statement of intent ever having been formed.

## The TPB, intention and behaviour

The TPB has been used in numerous studies in relation to both intention and actual behaviour among healthy and unhealthy populations, and across a wide range of behaviours, from preventive behaviours such as condom use, medication adherence, physical activity (PA), vaccination uptake or self-screening behaviour, to risk behaviours such as the converse of those just listed, plus behaviours such as smoking, illicit drug use, or binge drinking. For obvious reasons, this chapter can not address every behaviour in similar depth, therefore interested readers need to follow up on specific behaviours themselves. However we introduce the reader to several popular areas of research.

### Physical activity

In relation to physical activity of children, Hagger et al. (2001) found that attitudes, perceived behavioural control (PBC) and intention were significant influences on exercise behaviour assessed a week later. PBC and attitude both predicted the intention to exercise, but subjective norm did not. In contrast, subjective norm (as well as attitudes and PBC) were significant predictors of Canadian adolescents' intention to engage in regular physical activity, eat fruit and vegetables daily, and be smoke-free over a one-month period (Murnaghan et al., 2010). Such inconsistency of findings regarding the strength of influence played by normative beliefs may be partly explained by the age of the children (the Canadian sample were older than Hagger's sample (12–16 years compared to 12–14 years) and thus perhaps more responsive to social influence (Conner and Sparks, 2005) or perhaps measurement issues (see also 'Issues')).

Exploring the relationship between TPB components and physical activity among adolescent survivors of cancer, intentions to be physically active on a regular basis were predicted by affective attitudes towards physical activity (e.g. seeing it as enjoyable–unenjoyable) and instrumental attitudes (seeing it as useful–useless), but not by any of the other TPB components (34 per cent of variance explained in total). Physical activity itself was explained by intention (19 per cent variance explained) and by self-efficacy (added a further 10 per cent). This study assessed both PBC and self-efficacy and note that it is the latter that emerged significant (Keats et al., 2007), which is consistent with Armitage's study referred to above. That different components of the TPB explain intention than predict actual exercise behaviour

## ISSUES

### Normative beliefs and how we conceptualise and measure them

Generally, subjective norm (SN) is assessed by asking individuals to state what they believe the norms and expectancies of a range of spontaneously listed other people are in relation to the behaviour in question. In this method of questioning, an individual is prompted to think of many people or many influences and a '*modal' belief* is what is analysed. Steadman and colleagues (Steadman et al., 2002) argue that in modal beliefs there may be one or more highly salient belief that holds high importance to the individual, and that prediction of outcomes may be improved if such salient *individual beliefs* are analysed rather than modal beliefs. This hypothesis was partially confirmed in their findings, drawn from prospective longitudinal study of predictors of mammography uptake among 1,000 women. Comparing individual normative belief with modal beliefs there was no significant difference in the strength of their association with intention or attendance behaviour. However, individual normative beliefs added to the prediction of attendance at mammography, where modal beliefs did not. Earlier studies where an effect of SN on mammography attendance was not reported, may have relied on modal beliefs, and Steadman and colleagues conclude that 'an individually generated subjective norm is a more sensitive and accurate estimate of the true effect of normative pressure' (p. 327). Notably, by necessity, women who could not identify a normative influence on their behaviour were excluded in this analysis, yet such women would be worthy of separate investigation in that their decisions about screening uptake (or any other behaviours potentially) are likely to be made on a very individual basis.

A second consideration of subjective norms distinguishes between *descriptive norms* (i.e. which describe what others do, e.g. 'the majority of high school students try to eat sufficient fruit themselves') and *injunctive norms* (i.e. those that proscribe what you should do because others do it and think it appropriate you do too e.g. 'the majority of high school students think other high school students *should* eat sufficient fruit'). Following on from findings that adolescents underestimated peers' actual consumption (descriptive norm) and overestimate peers' negative attitudes towards fruit and vegetable consumption (injunctive norm) (Lally et al., 2011) it was proposed that studies should measure both types of norms.

Stok, de Ridder and colleagues (2014) did exactly this in an experimental study which involved manipulating perceived norms and recording participants' subsequent intended and actual fruit consumption.

For *intention* analyses, females, and those high on autonomous motivation reported higher intention to eat fruit and so these were controlled for in analyses related to intention. Results found that adolescents receiving the injunctive norm message reported significantly lower *intention* to eat fruit than those in both the descriptive norm and the control group (those latter two groups did not differ from each other).

In terms of subsequent reported *behaviour*, older individuals reported eating more fruit and so this and autonomous motivation was controlled for (it is unclear whether gender is again controlled for). In this case, greater fruit consumption was found in these who received the descriptive norm information compared to the injunctive norm group or the controls (and the latter two groups did not differ from each other).

These findings reveal different effects of injunctive and descriptive social norms, whereby injunctive norms negatively affected intention, and descriptive norms, in contrast, positively affected behaviour. While partially confirming the study hypotheses, the interest lies more in what was *not* associated. Firstly, the descriptive norm message affected behaviour but not intention, which is contrary to theoretically driven, TPB-led hypotheses that intention is the proximal determinant of behaviour. The authors suggest that this is because the broad description of others' behaviour acts as a quick and easy 'heuristic' – a rule of thumb that guides behaviour without the need for much conscious cognitive effort nor the need to first form explicit intentions to eat fruit. They just 'did' (or rather, report that they did). This has important implications for brief interventions.

Secondly, presentation of an injunctive message had a negative effect by reducing intentions to eat fruit among this adolescent sample. The authors suggest this may reflect adolescent resistance to a message suggesting how they *should* be behaving, although it is important to note that this negative effect did not emerge in relation to subsequent behaviour. Further study of the presence and duration of any resistance to injunctive messages would be useful.

To control for possible self-presentation bias (given the very norms that are perceived!) these authors simultaneously assessed participants' tendency to indulge in social comparison and report that social comparison tendency was not associated with reported intention or consumption of fruit.

What these studies highlight is a need to consider how we ask our questions and when we ask them. In addition, social norms do not always come from friends – a review of evidence (Gilliam and Schwebel, 2013) found that parental engagement in PA was an important influence on the child's levels of physical activity. However when considering adolescents within the sample, indirect parental support via encouragement and transportation (!) was more important than parental engagement, perhaps because peer behaviour takes on more **salience**. We further address the influences of parents and adolescents on each other's health behaviours in 'Research focus'.

**salience**
strength and importance

is consistent with findings of a meta-analysis of exercise behaviour among healthy populations (Hagger et al., 2002). As it is actual behaviour change that interventions wish to target these are the key findings (see Chapters 6 and 7 ☛).

### Vaccination

The TPB has been employed to try to gain understanding of factors associated with uptake of vaccination (see also Chapter 4 ☛). A UK study (Brabin et al., 2006) of 317 parents of 11–12-year-olds revealed a low level of intention (38 per cent certain, 43 per cent probable) to have their child vaccinated against Human Papilloma Virus (HPV), a virus known to cause about 70 per cent of cervical cancers (see also Chapter 3 ☛). Possibly one aspect influencing the reportedly low intentions to be vaccinated was widespread concern among clinicians as well as parents that vaccination would be viewed by teenage girls as a form of wider protection against other STIs (sexually transmitted infections), potentially increasing their sexual activity and exposure to risk. As noted previously, studies that assess actual uptake behaviours are needed if health promotion efforts are to be targeted effectively. Addressing this, a study of 339 girls and women aged between 13 and 21 who had the HPV vaccine and who were either sexually experienced or inexperienced at the time of vaccination (Mayhew et al., 2014) found no association between post-vaccination risk perceptions and sexual behaviour initiation among the sexually inexperienced in the subsequent six months. They also found no increase in the number of sexual partners, nor a change in condom use behavior reported by the sexually experienced participants. When looking at specific age groups it emerged that sexually inexperienced women aged 16–21 with inappropriately *low* perceptions of risk of other STIs, were in fact *less* likely to initiate sexual activity after vaccination. These findings countered concerns and possible barriers to being vaccinated. Of course as this sample consisted of those who *DID* present for vaccination, the findings do not tell us about the beliefs and behaviour in those who choose not to present for vaccination. Ideally therefore we actually need evidence of behavioural beliefs from those that do act, and those that do not!

It is also important to note that vaccination behaviour may be influenced by individuals perceptions of the disease they are seeking protection from, just as studies addressing behaviour change among those already living with cancer or heart disease need to also consider their perceptions of their illness (**illness representations**) (see Chapter 9 ☛). Perceptions of illness add to the explanation of behaviour, as do perceptions of the medical intervention or treatment.

For example, illness beliefs influenced help-seeking behaviour in those with breast cancer symptoms (Hunter, Grunfeld and Ramirez, 2003) and beliefs and concerns about medicaton influenced the critical health behaviour of adherence (e.g. Clifford et al., 2008; Morrison et al., 2015). Demographic factors such as age or ethnicity may also affect illness beliefs and thus preventative or help-seeking behaviour (see also Chapter 9 ☛ for a discussion of COVID-19 related beliefs and screening behaviour).

### Smoking

Smoking is fundamentally an individual behaviour requiring one person only for its performance. Smoking is talked about frequently although it is increasingly becoming marginalised in many countries. Social influence has however been identified as important to smoking uptake, for example in studies of child smoking uptake, parental influence is strong (e.g. Hiemstra, 2012) (see Chapter 3 ☛, and also 'Research focus'). Parental relationships and support can counter negative peer influences (Choukas-Bradley et al., 2014), and adolescents may behave differently at home than they do outside (Guidetti, Cavazza and Graziani, 2014). Beliefs in control over smoking behaviour, and in particular self-efficacy beliefs (as defined in the HAPA, below), have been found to be salient factors in relation to smoking cessation. Where past behaviour is constant, it may be said that we have acquired a habit, such as with smoking, i.e. it is a dependency-producing behaviour. Perhaps as a consequence, few studies have actually applied the TPB to smoking cessation, acknowledging that habitual behaviour is subject to different influencers and controlling factors than behaviour of a more **volitional** nature, such as condom use. When a behaviour, such as smoking, becomes a habit, the impulse to smoke can occur independent of our conscious cognitive efforts (Hofmann et al., 2008; as cited in Sutton 2010 and also Chapter 3 ☛). Dealing with habitual behaviours is a major challenge to behaviour change theory (Gardner, Rebar and Lally, 2019).

### Sexual risk behaviour

There are sufficient differences between smoking and sexual risk behaviour to perhaps expect that the predictors of each may differ. Unlike the individually performed behaviour of smoking, sexual intercourse typically involves two people in a social encounter or interaction. In addition, dependence is rare in relation to sexual behaviour, although compulsive sexual behaviour has been described as addiction, (Reid, 2016). Sexual behaviour, particularly that carrying risks such as unprotected sexual intercourse, is not typically discussed in public.

Studies drawing from the TPB with regards to sexual behaviour have predominantly focused on identifying factors associated with increased condom use. A meta-analysis of studies found that previous use of condoms, a positive attitude towards use, subjective norms of use by others, partner support of use, self-efficacy in relation to both the purchase and use of condoms, and intentions are important (see Albarracin et al., 2001). TPB components typically perform moderately well at predicting intentions to use condoms, and intentions tend to relate to behavior, but overall the TPB components are less strongly predictive of actual behaviour (McEachan et al., 2011). Such findings are contrary to the theoretical assumptions that behaviour would follow intention (which was predicted by the attitudinal and cognitive components) which led research to address the 'intention-behaviour' gap (Hagger and Luszczynska, 2014, discussed below).

One critical limitation of studies of condom use is that many have been conducted with educated young adult populations (e.g. students) rather than in more 'chaotic' populations for whom behaviour change is crucial, for example among sex industry workers. It is important to address whether sexual partners are long-term or casual

illness representations

beliefs about a particular illness and state of ill health – commonly ascribed to the five domains described by Leventhal: identity, timeline, cause, consequences and control/cure

volitional

behaviour following deliberate or reflective processes rather than those which are automatic or impulsive as this will affect the actual and possibly perceived risk of not using a condom as well as potentially influence the attitudes towards 'safe sex' and whether it is necessary or important (e.g. MacKellar et al., 2007). It has been suggested that for some individuals the use or non-use of condoms is less governed by intention (and by implication the cognitive processes that the TPB claims precede intention) than by habit, and, as such, interventions should be targeted very early in a sexual career so as to facilitate the development of 'safer sex' habits (cf. Yzer et al., 2001).

## Beyond the TPB

Several limitations of the TPB were noted across the decades of studies using this model to try and explain behaviour and behaviour change, including the fact that the TPB does not acknowledge likely bi-directional relationships between predictors (attitudes and subjective norms) and outcomes of either intention or behaviour. We get feedback from our behaviours that may change our beliefs and expectancies; rarely are our beliefs or behaviours static! Many published studies were cross-sectional and without prospective longitudinal evidence any changing relationships between variables over time can not be established, neither can those variables which offer intervention potential be identified.

In fact, when the prediction of behaviour from TPB variables is significantly lower than their prediction of intention, then the utility of a model for developing behaviour change interventions is limited. Although intention was theorised as the critical precursor of behaviour change, intervening to increase intention (by targeting normative or PBC beliefs for example) has not had a huge effect on behaviour. In fact, a meta-analysis of experimental changes in intention-behaviour relationship with regards to physical activity found that medium-sized changes in intention only resulted in trivial-sized changes in behaviour (Rhodes and Dickau, 2012). Perhaps accounting for this is the problem that the TPB, as with most models of health behaviours, have assumed that the same factors and processes predict the initiation of a behaviour or initiating a change in behaviour as predict its maintenance over time. A review of over 100 theories of behaviour initiation and maintenance shows this not to be the case (Kwasnicka et al., 2016). The majority of studies however focus on behaviour initiation which may be why interventions based on their findings have had only small to medium effects on prolonged behavour (for example, healthy eating, de Ridder et al., 2017) or failed to have long-term effects on behaviour change maintenance (van Stralen et al., 2009). In addition as many studies have not used any or adequate control groups, it is difficult to reliably identify critical ingredients for change.

From rigorous review and evaluation of the limitations of the TPB over the past four decades, several other concepts have emerged as useful additions to TPB studies. The original TPB authors (Fishbein and Ajzen, 2010: 282) advised that additional predictors should be added 'with caution, and only after careful deliberation and empirical exploration', and that any additions should be 'conceptually independent of the theory's existing predictors'. Over the past 15–20 years, several additional components have been investigated, with substantial empirical success. There is now strong evidence that past behaviour, affective (emotional) variables (e.g. anticipatory regret) (Ferrer and Mendes, 2018), those that relate to planning processes (e.g. implementation intentions), self-regulatory processes including self-efficacy, attentional control and those that acknowledge automaticity or habit can predict health behaviour, over and above TPB measures (Sniehotta, Pressau and Araujo-Soares, 2014). These are detailed briefly below.

### Past behaviour

The best predictor of what you intend to do today is likely to be what you have done in the past. For example, trying to stop smoking is influenced by whether or not you have tried to before as this will influence your beliefs in whether or not you can stop smoking (PBC) and whether you are likely to succeed (outcome expectancy). In fact adding past quitting attempts to TPB variables added significantly to the prediction of quitting intentions among 357 daily smoking students in Norway (intention increased with the number of prior quit attempts) (Hoie et al., 2010). Importantly however, Vangeli and colleagues (Vangeli et al., 2011) find no clear association between past attempts to quit and actual success in stopping at the next attempt. However, as noted by Fishbein and Ajzen (2010: 286), examining past behaviour tells us what we did and predicts what we now do, but it does not tell us 'why'. Perhaps surprisingly any effect of past behaviour appear not to be fully mediated by the core TPB components – attitudes, norms, PBC.

## RESEARCH FOCUS

### Interpersonal effects of parents and adolescents on each other's health behaviours: a dyadic extension of the TPB

Joyal-Desmarais, K., Lenne, R.L., Panos, M.E., et al. (2019). Interpersonal effects of parents and adolescents on each other's health behaviours: a dyadic extension of the theory of planned behavior. *Psychology & Health*, 34: 5690589.

### Introduction

The majority of the models of health behaviour reported in the literature and presented in this chapter focus on the individual, the intrapersonal influences on a person's behaviour and pay limited attention to the role played by interpersonal influences. The considerations of other people's influence for example in the TPB, are reflected in a measurement of an interpersonal judgement, the perceived Subjective Norm, and it is this that is tested in relation to behaviour. The actual effect of the interpersonal factors are thus hidden.

### Methods

To address the question of whether a significant others' beliefs and behaviour affect another person's beliefs and behaviours, this study reports findings from an impressive survey of 1,717 parent and adolescent dyads. Dyadic modelling enables the examination of intrapersonal (termed 'Actor') effects i.e.

- Person A's beliefs and their impact on Person A's intentions and behaviours;
- Person B's beliefs and their impact on Person B's intentions and behaviours;

but critically it also enables the examination of interpersonal (termed 'Partner') effects i.e.

- Person A's beliefs and their impact on Person B's intentions and behaviours;
- Person B's beliefs and their impact on Person A's intentions and behaviours.

The authors consider both positive health behaviours – engagement in physical activity (PA), eating fruit and vegetables (FV), and negative health behaviours – consumption of junk food and sugary drinks (JF), engagement in sedentary screen time behaviour (SB). The study measured the TPB attitudes, Subjective Norms, Perceived Behavioural Control (PBC) and intentions for both members of the dyad – a parent (74 per cent mothers), and adolescents aged 12–17 years (50 per cent male, 50 per cent female). All the data were scored in a consistent manner so that higher scores reflect positive beliefs or intentions to engage in the relevant behaviour. Attitudes were limited to one item per behaviour – '*I would [engage in behaviour [x] every day because it is an important thing for me to do*', with two extra items addressing PA (fun, liking). Subjective Norm for each behaviour was assessed by two items: a descriptive norm for adolescents only ('*My friends [engage in behaviour [x] most days of the week*) and an injunctive norm for parents and adolescents ('*I would [engage in behaviour [x] because others would be upset with me if I didn't*'). One item for each behaviour assessed Perceived Behavioural Control in both members of the dyad ('*I feel confident in my ability to [engage in behaviour* [x]'). Finally, intentions were measured with one item ('*I would [engage in behaviour [x] because I have thought about it and decided that I want to [engage in behaviour* [x]').

Each of the four behaviours were assessed using age-appropriate and standardised items. FV and JF consumption behaviours were assessed in the same way for parents and adolescents in terms of their frequency over the past seven days. PA however was assessed differently, with adolescents reporting PA frequency over the last week in school time and in free time, whereas parents reported their PA over the last week also in relation to intensity. For SB the average free time spent per day on a computer, mobile phone, TV or videogame was assessed in adolescents, with parents completing similar, but not identical items.

The authors model the effect of beliefs on behaviour indirectly *via* intention, as the TPB proposes (Model 1) but also directly (Model 2). The analysis uses an increasingly popular statistical method, the Actor-Partner Interdependence Model (Kenny, Kashy and Cook, 2006) (see also Chapter 15 ☛ in relation to patients and caregivers) which employs structural equation modelling to identify Actor effects e.g. the intrapersonal effects of adolescent attitude on their own behaviour, and Partner effects, e.g. the interpersonal effects of parent attitude on adolescent behaviour or vice versa.

## Results

The TPB assumes 'Actor effects' whereby a person's attitudes, SN, PBC should be positively associated with their Intention, and their intention should then associate with behaviour (Model 1, indirect). Testing Model 1, 31 of the 32 Actor effects tested among the parents and adolescent sample were positive and significant. For Model 2 where beliefs could have direct effects on behaviour (rather than via intention), 28 of the 32 were positive and significant. PBC had a direct effect on three of the four parental behaviours (not PA) but on all four adolescent behaviours. Parents' attitudes directly explained everything except their Sedentary Behaviour, and for adolescents, attitudes only explained their PA. Parents SN influenced all their behaviour except FV consumption but was actually negative for JunkFoodf intake and Sedentary Behaviour, whereas in contrast adolescents SN positively influenced all their behaviours. Thus Actor effects were clearly seen, significant and were generally speaking in the theorised direction.

Important findings also emerged regarding Partner effects, although there were fewer than Actor effects – 13 Partner effects emerged in the indirect Model 1 and 21 in the direct Model 2. The paper reports quite a complex modelling (which I will not detail here) but it is noted that both the frequency of significant Partner effects and their average magnitude are presented. Across the four behaviours there were fewer significant effects going from adolescent beliefs or behaviour to parent beliefs or behaviour (five effects in Model 1, ten in Model 2) than from parent to adolescent (eight effects in Model 1, eleven in Model 2), but the average magnitude of effect was similar. The frequency pattern is similar when intention is accounted for, although the magnitude of effects are smaller. When behaviour is accounted for however, the adolescent-parent effects are more often significant that the parent-adolescent effects in Model 1. In both models, the average magnitude of adolescent–parent effects was greater than those from parent–adolescent. Subjective Norms had the largest number of partner effects on both intention and behaviour. Attitudes associated only with partner intentions and not the behaviours. PBC was associated with several partner behaviours, but fewer intentions.

## Discussion

This excellent paper addresses the role of the interpersonal domain in the performance of health behaviours among adults as well as adolescents using a method that enables such effects to be considered *above and beyond* that of the intrapersonal i.e. these are controlled for in the Partner analyses. This basically recognises that members of a dyad such as adolescents and their parent are non-independent. Partner effects above the actor effects were found for all behaviours and on both intention and behaviour, suggesting that partner effects don't just work via changing actor beliefs.

Particularly novel findings are presented with regards to the effect of adolescents on their parental health behaviours – this is rarely considered apart from perhaps in relation to food consumption! While stronger associations were seen between parent beliefs and adolescent intentions, than between adolescent beliefs and parent intentions, adolescent beliefs had stronger effects on parent behaviours, than parent beliefs had on adolescent behaviours. Perhaps parents shape their adolescents intentions . . . but perhaps these intentions are lost when competing influences, such as interpersonal effects of peers, are encountered (a study of other interpersonal influences is needed to explore this, perhaps a triadic analyses- adolescent-parent-peer!). In contrast adolescents are better able to influence parental intake of junk food or participation in video game play, even if this goes against parental intention, i.e. parents may occasionally capitulate to a demanding adolescent? Again further research is needed to disentangle some of these effects and the shifting power dynamic from a younger to an older adolescent perhaps.

The study also considers positive as well as negative health behavior, which enables the question of

*(continued)*

whether interpersonal effects vary by behaviour type. We know already that TPB constructs have variable effects on different behaviours and this dyadic study confirms that. Intentions were more strongly implicated in healthy behaviour (FV, PA) than the unhealthy (JF, SB) which fits with thinking that unhealthy behaviours are under more impulse control rather than delibarative (Wiers and Hofmann, 2010). Surprisingly a positive parental Subjective Norm was related to higher adolescent intake of Junk Food and Sedentary Behaviour – perhaps this reflects a perceived 'injunctive norm' with adolescents rejecting this expression of authority.

This interesting study is, however, limited by its cross-sectional design which prevents any observations of causality, in fact the behaviours themselves may account for differences in the beliefs and intentions rather than the reverse! In addition the sample characteristics limit the generisability of its findings as all parents were female, and 70 per cent of parents and 64 per cent of adolescents were white. Finally, there are some issues around conceptual measurement – the large USA national survey (FLASHE study), which this study attached to was not designed to explicitly employ a TPB questionnaire and thus items were selected which best 'fitted' the constructs of interest. This led to a restricted number of items assessing each TPB construct, and variations in the wording used per behaviour, including the timeframe of assessment, all of which may have influenced cognitive demand and limits comparability between behaviours and between parent and adolescent measures. Finally, there was no measurement of the quality of the relationship between an adolescent and their parent, in terms of communication, caring, cooperation and mutual respect etc., which means that an important potential moderator of the relationship between one members beliefs and anothers behaviours can not be considered.

This study is therefore not without its flaws. That said it remains an impressive sample, it asks important questions, gives clear thought to its limitations in the analysis planning, and raises several questions for future research to address. Thus it is included here!

Past behaviour, if frequent and consistent, can also develop into habit, which brings further challenges to those seeking to change behaviour.

### Habits and automaticity

Non-reflective action, or automatic action is when you engage in a behaviour but are barely conscious of doing it, such as brushing your teeth – sandwiched into a morning and evening routine along with washing, showering, shaving or putting makeup on at the mirror above the sink, done without much thought, but with the action being triggered by facing the mirror rather than conscious decision-making. Habits form through repeated performance in relatively stable contexts which often then act as automatic triggers of the behaviour and thus habits don't use up cognitive resource in the way that forming attitudes or perceived control beliefs might. Habits can override competing intentions, i.e. having the habitual morning cigarette with that first coffee can defeat intentions to do otherwise. Habits can become automatic to the point you may sometimes ask yourself whether you did them or not. Awareness of performing a habitual behavior is only achieved on being presented with the consequences – 'I don't recall doing my teeth, yet I have white paste all over my chin: therefore I must have done so!' (adapted from smoking example of Sniehotta and Presseau, 2012, as cited in Gardner and Tang, 2014). Habits can be problematic for those seeking behaviour change (see 'Stop and think').

### Anticipatory emotions

Sociocognitive models, including the TPB, have been criticised for insufficient consideration of how emotion or affect might influence attitudes, perceived norms and PBC and thus behavioural intention and behaviour, or examining whether in fact emotions have direct effects on intention or behaviour. Many models of health behavior, such as the HBM and the TPB, assume we act rationally on the basis of our cognitions (attitudes, beliefs and expectations) in a certain social context. However emotions can accompany these cognitions. Perugini and Bagozzi (2001) propose that anticipatory emotions arise from a person's consideration of the likelihood of succeeding or failing in achieving desirable outcomes of a behaviour (outcome expectancies). Studies of anticipatory regret (Bell 1982; van der Pligt and de Vries, 1998) i.e. where a behavioural decision would lead to anticipation of an undesireable future outcome (e.g. 'If I do not use a condom I would really regret it if I got pregnant/If I got an STD') report significant improvements to the prediction of a range of behaviour. A meta-analysis of 24 datasets (Sandberg and Conner, 2008) found that anticipated affect (not just studies of anticipatory regret, but also anticipatory sadness, worry, and some studies of anticipatory positive affect such as feeling proud or exhilarated) added 7 per cent to the explanation of a range of behavioural intentions, but only 1 per cent to explaining behaviour. More recently a meta-analysis of 81 studies involving more than 45,000 participants, (Brewer, deFrank and Gilkey, 2016) distinguished between 'action regret' (i.e. regretting doing something), and 'inaction regret' (regretting not doing something), and found that while both types of regret significantly explained behaviour, inaction regret was the stronger predictor of both intention and behaviour. Anticipated affective reactions to behaviour change (or non-change) make a small but significant contribution. When anticipating negative affect is not associated with behaviour change (for example, when anticipating a hangover does not reduce a night's drinking), this may suggest that the perception of the behaviour itself (e.g. drinking less) may moderate the effect of anticipatory regret. Anticipatory affect is likely linked to attitude formation.

### Moral norms

Some intentions may more likely translate into behaviour where intentions align with moral norms, particularly behaviours that directly involve others, such as condom use or drink driving (e.g. Evans and Norman, 2002; Godin, Conner and Sheeran, 2005).

### Self-identity

How one perceives and labels oneself using socially meaningful categories, roles and traits has been shown to influence intention above and beyond the effect of core TPB variables, and the normative components specifically (for example, increased young adults' intentions to seek chlamydia testing, Booth et al., 2014). We tend to behave in a manner that affirms our self-image. A meta-analysis of 24 sets of data found that including self-identity increased the prediction of intention by 13 per cent, which is considerable (Rise et al., 2006). In relation to actual behaviour, Carfora, Caso and Conner (2016) report an independent effect of self-identity as a healthy eater on future fruit and vegetable intake behaviour when controlling for TPB variables and also for participant's past behaviour. The implication of self-affirmation as an intervention tool, whereby people are encouraged to reflect on cherished values or attributes of themselves as a means of enhancing risk processing and acceptance, in order to promote behaviour change, is seen in Epton and Harris (2008) (fruit and vegetable intake), or van Koningsbruggen et al. (2009) (caffeine intake). Self-identity is also a core component of evaluations outlined in West's (2006) PRIME theory as applied to addiction including smoking, where a person's **P**lans, **R**esponses, **I**mpulses, **M**otives and **E**valuations are considered together, acknowledging the role played by experience, impulses, cognitions and motivations and evaluations of self and other in a person's health behaviour. Due to its integrated nature PRIME theory has been used to underpin the development of a behaviour change intervention for smoking cessation (e.g. Michie et al., 2011).

## STOP and THINK

How can we measure habit if at times we carry out such behaviours without really thinking? Could you accurately tell a researcher how long you brushed your teeth for this morning or how many times last month you took a lift instead of taking the stairs? If we are to effectively help people who wish to substitute an unhealthy habitual behaviour with a more healthy habit, we need to better understand unconscious actions. Our dominant models tend to assume conscious awareness and relatively rational cognitive effort – neither of which are inevitable! How do we accurately assess characteristics of a behaviour when its performance is automatic? One example is to use think-aloud methods, for example Gardner and Tang (2014) asked students to speak their thoughts aloud while completing habit measures relating to snacking, commuting using public transport, and alcohol consumption. 90 per cent of participants in this necessarily small qualitative study (N = 20) reported difficulties in recalling their behaviour or the cues for them, or lacked confidence answering questions about the extent to which their behaviour was performed automatically. So the validity and usefulness

*(continued)*

of measuring habit is questioned. Why does this matter? It matters if you have a 'bad' habit, such as that cigarette you light without thinking while waiting for the kettle to boil, as that may not lend itself as easily to intervention as the cigarette you deliberate over. Creating new, healthy habits, takes time and perseverance, and firstly we need to identify what parts of behaviour are habitual, what the cues are etc. Few studies have as yet attempted this. A lack of this understanding may explain why the dominant models such as those described in this chapter, each of which is underpinned by an assumption of conscious awareness and cognitive effort, do less well than theorised when it comes to habits . . . good or bad!

### Action planning and implementation intentions

Gollwitzer suggests that individuals need to shift from a mindset typical of models (such as the TPB) examining attitudes, beliefs and motivations (pre doing) towards an implementational mindset, which is found in the **volition** (doing) phase (Gollwitzer, 1999; Gollwitzer and Schaal, 1998; Gollwitzer and Sheeran, 2006). Gollwitzer describes how individuals need to make a specific 'If–Then' statement (known as an 'implementation intention'), for example, 'If I go out with my friends, then I will not drink'; with intention containing a 'when, where (context, e.g. in this example, 'with friends') and how' plan that commits them to a certain situation where they will use a particular method of action. For example, rather than stating, as is typical in the TPB measures, how strongly I intend to start a diet, an implementation intention would require me to state that I intend to start my diet next Monday, at home, with a healthy breakfast.

One reason why people may not always translate their good intentions into action (the 'inclined abstainers'; Sheeran, 2002) is that they have not made adequate plans as to how, when and where they will implement their intention. Action planning can be cognitive in terms of making a mental note of when, where and how one intends to perform a behaviour, typically operationalised as forming an *implementation intention* (II), however it can also be behavioural in terms of carrying out 'preparatory' behaviours. For example, for condom use, this could include mental planning of condom purchase or use, or actual behavior such as buying condoms or talking to a potential partner about their use (Potard, Caballero and Courtois, 2017).

Implementation intentions are thought to increase a person's commitment to their decision by creating a type of mental representation of a good opportunity (e.g. next Monday) to act in an intended way (e.g. starting a diet) that is accessible in one's memory and which therefore increases the likelihood of carrying out the intended action (Gollwitzer and Brandstätter, 1997). IIs obtain their effects by making action more automatic, i.e. in response to a situational stimuli set down in the II. It has been demonstrated that IIs can promote the performance of an intended behaviour even without conscious intent – the context itself cues the if-then action, an 'intention activation" (Bayer, Achtziger, Gollwitzer and Moskowitz, 2009; Sheeran et al., 2005).

The role of IIs in attaining a wide variety of specified health-related goals has since been confirmed in various meta-analyses (mixed behavioural studies, Gollwitzer and Sheeran, 2006; physical activity studies, Belanger Gravel et al., 2013). Among university students, for example, where binge drinking is a concern, forming a II was found to increase the likelihood of strong intentions to reduce drinking being translated into action (Norman, Webb and Millings, 2019). In addition, while there is evidence that forming proximal (more immediate) goals leads to better goal attainment than forming distal (long-term) goals, IIs do show persistence over time. For example, with regards to physical activity, a meta-analysis of 26 datasets found that a consistent small-to-medium effect of forming IIs on physical activity was not reduced in studies with longer follow-up periods: i.e. the effect sizes were similar (Belanger-Gravel et al., 2013). Such findings have implications for a wide range of groups where brief interventions are more feasible than prolonged intervention; for example, hospitalised patients could be encouraged to form IIs about their home-based rehabilitation prior

volition

action or doing (the post-intentional stage highlighted in the HAPA model of health behaviour change) to discharge in order to improve exercise adherence (and hence recovery) post-discharge. Some people spontaneously form IIs when they form a motivational intention ('I intend to exercise every morning after breakfast'); however, many others do not and could benefit from such an intervention (see Chapter 6 ☛).

De Vet and colleagues (de Vet et al., 2011) rightly point out that much of the evidence of positive effects of II formation on behaviour comes from research studies where individuals were helped to form their II, which is of course not always available in real life. They demonstrated variation in the quality of IIs developed independently by young single females aged between 16 and 30 years regarding 'preparing' to buy a condom and actually 'using' the condom. Results showed that IIs were of better quality (sufficiently complete and precise) in relation to preparation (buying) than for actual sexual activity, but in fact IIs were not predictive of all preparatory behaviours (buying, having condoms at home, discussing with potential partner). In spite of some sample restrictions, such findings serve to highlight that effective planning for condom-use behaviour is complex.

### Coping planning

Coping planning involves anticipating and planning for how to deal with barriers to behaviour (Molloy et al., 2010; Sniehotta et al., 2005), It has been suggested that drawing up an Implementation Intention for preparatory action should be encouraged rather than targeting IIs to the behaviour directly. This would encompass the formulation of plans for barrier management: for example, 'IF I encounter a friend who smokes, THEN I will tell them straight away that I have stopped'. Molloy and colleagues (Molloy et al., 2010) found that female students benefited from social support for physical activity more than males, and but that the influence of social support on subsequent physical activity was partially mediated by both their PBC and coping planning.

Studies of behavioural prediction do now generally include a measure of II. Importantly, there is growing evidence that forming an II may also be able to help in replacing unhealthy habitual behaviour with a healthier option, although findings and study designs have been mixed (experimental vs 'real-life' studies, samples with different strength of habits for example). In relation to eating behaviour, Adriaanse and colleagues (Adriaanse et al., 2011a) found that the effect of IIs was stronger for increasing heathy eating than for decreasing unhealthy eating. A further example is provided by Webb and colleagues (Webb et al., 2009), where forming an II was found to be effective in reducing smoking behaviour among adolescent smokers *only* when smoking was light–moderate rather than heavy. In a later review specific to attempts to change addictive behaviour, Webb et al. (2010) describe how habits may not be subject to the same conscious controls and that such interventions may require greater consideration of issues around self-control.

### Goals and goal intentions

Generally, we succeed in achieving our goal when we value the likely outcome; believe that the goal is attainable through our actions, i.e. self-efficacy; and when we receive feedback on progress made (this is particularly important where long-term goals, such as weight loss, are involved). When trying to replace an unhealthy behaviour, particularly a habitual one, with a more healthy behaviour it has been suggested that more than an II to perform the healthy behaviour is needed to result in the choice always being with the 'good', counter habitual behaviour (Adriaanse et al., 2011b). This could be self-control perhaps, or perhaps action will depend on the salience of the competing 'goal intentions', i.e. to truly 'break habits', the goals sought by carrying out the new healthy behaviour need to be valued.

In conclusion, nowadays most studies have adopted extended TPBs, including many of the concepts described above. Some have proposed that given highlighted limitations -limited tests of the TPB in relation to behaviour as opposed to intention, limited longitudinal designs, fewer general population or risk population samples as opposed to educated student samples, and few incorporating objective outcome measures rather than self-report – the original TPB has perhaps served its purpose (Sniehotta, Pressau and AraujoSoares, 2014). Attention has turned to models that appear to more fully explain behaviour and offer avenue for intervention. These models of behaviour change consider individuals as being at 'discrete ordered stages' each one denoting a greater inclination to change behaviour than the previous stage (Rutter and Quine, 2002: 16) and which by definition assume that interventions would target different factors at different stages. Maintaining behaviour change will rely on continued motivation and maintained self-efficacy and these may fluctuate over time (Kwasnicka et al., 2016; Voils et al., 2014). Research needs to evolve to consider these in prospective designs.

### STOP and THINK

The questions we ask may effect subsequent behaviour, sometimes referred to as 'mere measurement effects' (Morwitz et al., 1993, as cited in Godin et al., 2008: 179). For example, a questionnaire assessing perceived susceptibility to an illness may increase awareness of the illness, cause the individual to reflect on their own behaviour, change their belief structure, or, potentially, even their behaviour. In one study examining beliefs and intentions about hypothetical genetic testing uptake for breast cancer (Morrison et al., 2010), participants rated their attitudes towards genetic testing, their outcome expectancies, perceived benefits of, or barriers to testing, and their intention to undertake testing were it to become available. Such questions may have caused some individuals to think about something they had not thought of previously. The questions also provide information to the participant about the behaviour: for example, 'To what extent do you think that genetic testing will: reduce uncertainty about my long-term risk of breast cancer?; enable me to make positive decisions about my future?', and this could potentially change beliefs and attitudes. This was reported in a study of intention to donate blood (Godin et al., 2008) whereby 2,900 adults who completed a TPB-derived questionnaire were significantly more likely to register for donation and subsequently donate blood than a control group of 1,772 adults who did not receive a questionnaire. In effect, the questionnaire itself acted as an intervention – and a relatively cheap one at that! Perhaps the direction of behaviour change could be manipulated by changing the wording of the questions used, in the same way as other studies attempt to change beliefs by manipulating the nature of information provided. While this may be desirable in certain circumstances, the issue of questions as interventions requires greater acknowledgement in research design and in the discussion of findings.

## Stage models of behaviour change

Another approach taken to the study of health behaviour is one which explicitly considers change as a process, with theoretical models developed where individuals are considered to be at different stages of 'readiness' to change depending on a range of factors. The goal of such models is to open up opportunities for intervention (see Chapter 6 ☛).

A stage theory requires four properties (Weinstein et al., 1998; Weinstein and Sandman, 2002):

1. *A classification system to define stages*: stage classifications are theoretical constructs, with a prototype defined for each stage (it is accepted that few people will perfectly match the ideal prototype).
2. *Ordering of stages*: people must pass through all the stages in the defined order to reach the end point, but reaching the end point is neither inevitable nor irreversible. For example, a person may decide to quit smoking and not do so; or may quit smoking but lapse back into smoking sometime thereafter.
3. *Similar barriers to change face people located within the same stage*: this would be helpful in encouraging progression through the stages: for example, if low self-efficacy acted as a common barrier to everyone in their *initiation* of dietary change, but a lack of social support acted as a barrier to *maintenance*.
4. *Different barriers to change face people in different stages*: if the barrier (e.g. low self-efficacy) to moving to the next stage were the same regardless of starting stage, then the concept of stages would be redundant. Ample evidence exists that barriers are different in the different stages (see below).

The next two models presented are the most commonly used stage models.

### The transtheoretical model (TTM or 'Stages of Change (SoC)' model)

This model was developed by Prochaska and di Clemente (1986) to describe processes of elicitation and maintenance of *intentional* behavioural change with regards to smoking cessation. Subsequently 'stages of change'

**Photo 5.3** How questions are asked and how they are scored may influence the responses obtained.

*Source*: Chad McDermott/Shutterstock.

have been examined in many other behaviours, including for example, cocaine use, alcohol use, exercise, condom use, sunscreen use, dietary fat intake, and mammography screening (di Clemente et al., 1991; Prochaska, 1994; Prochaska et al., 1994; Armitage, 2009). The model makes two broad assumptions: that people move through stages of change; and that the processes involved at each stage differ and are independent, thus it meets several of Weinstein's requirements.

## Stages of change

The stages of change proposed by the TTM are stages of motivational readiness. These are outlined below, using dietary behaviour as an illustration:

- *Pre-contemplation*: a person is not currently thinking of dieting, no intention to change food intake in next six months, may not consider that they have a weight problem.
- *Contemplation*: a person demonstrates awareness of a need to lose weight but without detailed thought of the mechanisms: for example, 'I think I need to lose a bit of weight, but not quite yet'. Generally assessed as planning to change within the next six months.
- *Preparation*: a person is ready to change and sets goals as to how to achieve this, such as planning a start date for the diet (within three months) or stocking up on healthy options.
- *Action*: actual behaviour change: for example, a person starts eating fruit instead of biscuits.
- *Maintenance*: keeps up with the dietary change, resists temptation (for longer than 6 months).

While the above stages are the five most commonly referred to, there are also:

- *Termination*: behaviour change is established after being maintained for adequate time (five or more years) so the person feels no temptation to lapse and believes in their total self-efficacy to maintain the change.
- *Relapse*: A person may lapse into earlier behaviour patterns and return to a previous stage. This is common and can occur at any stage, i.e. it is not a final stage or alternative to termination (di Clemente and Velicer, 1997).

People do not necessarily move in a linear fashion from one stage to another, for example, some individuals may go from preparation back to contemplation and stay there for months or years before re-entering the preparation phase and successfully moving on to action. For others action can fail, maintenance may never be achieved, and relapse is common. The model therefore allows for 'recycling' from one stage to another and is sometimes referred to as a 'spiral' model.

The first two stages are generally considered defined by intention or motivation; the preparation stage combines intentional and behavioural (volitional) criteria, whereas the action and maintenance stages are purely behavioural (Prochaska and Marcus, 1994). A key implication of the model is that there is little point in targeting interventions of the 'how to' type at pre-contemplators, whereas an intervention at that stage may wish to address awareness of risk and 'susceptibility' beliefs instead.

To help understand what influences progression through the stages, the model outlines independent psychological '*processes of change*' that are considered to be at play in the different stages (with some being important in more than one stage). These processes include the covert or overt activities that people engage in to help them to progress from one stage to the next: for example, seeking social support and avoiding settings that 'trigger' the behaviour, as well as more 'experiential' processes that individuals may go through, such as consciousness raising, weighing up the pros and cons of changing or reevaluating one's self identity. These cognitive and behavioural processes offer targets for intervention efforts to firstly motivate individuals to change and then 'move' individuals through the stages towards effective and maintained behaviour change (see Chapter 6 ☛).

- In the *pre-contemplation* stage, individuals may be using denial about the health issues' relevance to them, and/or may report lower self-efficacy (to change) beliefs and more barriers to change. Consciousness raising may increase the likelihood of progression to Contemplation.
- In the *contemplation* stage, people are more likely to seek information and may report reduced barriers ('cons') to change and consider increased benefits, although they may still underestimate their susceptibility to the health threat concerned. Some reevaluation of the problem's relevance to their health may facilitate progression to the next stage.
- In the *preparation* stage, people start to set their goals and priorities, and some will make concrete plans (similar to IIs described earlier) and small changes in behaviour (e.g. joining a gym). Some may set unrealistic goals for success, or underestimate their own ability to succeed. Motivation, self-efficacy and increased awareness of alternative behavioural choices are crucial if action is to be elicited.
- In the *action* stage, realistic goal setting is crucial, as is counter-conditioning which follows engagement in new healthier behaviour. The use of social support provides reinforcement that will help to maintain the lifestyle change.
- Many individuals will not succeed *in maintaining* behavioural change and will relapse or 'recycle' back to contemplating a future attempt to change. Maintenance can be enhanced by self-monitoring and planning rewards (i.e. reinforcement).

Several motivational factors vary across these stages: for example, perceived behavioural control and attitudes to activity (Lorentzen et al., 2007), outcome expectancies and anticipated affective consequences (Dunton and Vaughan, 2008), and perceived barriers and benefits, or 'pros and cons'. Evidence from a meta-analysis of the pros and cons relative to 48 different behaviours reveals that there were more 'pros' in the action stage than in the pre-contemplation stage, and less 'cons' in the action stage than in the contemplation stage (Hall and Rossi, 2008). An individual in the contemplation stage is likely to focus on both the pros and cons of change, but the 'cons' or barriers may be weighted more heavily (e.g. 'Even if I get healthier in the long term, I am probably going to gain weight if I stop smoking'), whereas someone in the preparation stage is likely to focus more on the pros of change (e.g. 'Even if I gain weight in the short term, it will be worth it to start feeling healthier'). The relative weight between pros and cons is referred to as **decisional balance**. The extent to which people weigh up pros and cons, as well as self-efficacy, was theorised to mediate the relationship between the processes of change and progress through the stages (cf. Prochaska and Velicer, 1997) although empirical evidence of this is relatively limited.

## The TTM and behaviour change

Some support for interventions based on staged models exists, for example, from studies of physical activity uptake, both among general public and patient populations (Armitage, 2009) (and see Chapter 6 ☛). A longitudinal trial of an exercise behaviour change programme, promoting either 'moderate' or 'intense' exercise,

decisional balance

where the costs (cons) of behaviour are weighed up against the benefits (pros) of that behaviour among sedentary Australian women aged 40–65 found that self-efficacy and decisional balance influence changes in exercise behaviour (Cox et al., 2003). When reassessed after 18 months, increases in self-efficacy were in line with the 'stage of change' achieved (i.e. self-efficacy increased as the stage progressed towards action) and appeared to be critical, whereas decisional balance findings were inconclusive.

Some of the assumptions of the TTM have been tested in intervention studies (see Chapter 6 ☛), where targeting the processes of change has not consistently resulted in the anticipated movement between stages. A systematic review of the findings of 37 controlled interventions studies provided limited support for stage appropriate interventions (Bridle et al., 2005), which led to calls for an end to TTM based interventions (e.g. Sutton, 2005; West, 2005), although subsequent studies do continue to provide some support (Hall and Rossi, 2008). Rhodes and colleagues (2017) note in their review however that most of our knowledge of successful intervention comes from data provided by those who were motivated to take part in an intervention, which carries obvious bias.

## Limitations of the TTM

- Are the theorised motivational factors necessary for change? Several studies have questioned whether the proposed processes are in fact useful predictors of change. For example, Segan et al. (2002) examined changes in self-efficacy and decisional balance among 193 individuals who were preparing to stop smoking and making the transition to the action stage and concluded that some changes in TTM processes (e.g. increased situational confidence, counter-conditioning) resulted from the transition to action, rather than preceded it, although the TTM claims that these would act as 'catalysts' for change. Furthermore, although self-efficacy was associated with making a quit attempt, it did not predict the success or failure of that attempt, nor was decisional balance predictive of any behaviour change, as seen in Cox's study of exercise. While such findings question the validity of the TTM stages and processes they highlight the central role of self-efficacy – which is central to the next model we discuss, the HAPA (below).
- Prochaska and di Clemente suggested a time-frame within which they distinguish contemplators from preparers (i.e. thinking of changing but not in the next six months versus thinking of changing within the next three months). There is, however, little empirical evidence that these are qualitatively different or differ in terms of the attitudes or intentions of stage members (e.g. Godin et al., 2004). This has implications for the likely effectiveness of stage-tailored interventions (Herzog, 2008).
- The validity of five independent stages is challenged by data that did not succeed in allocating all participants to one specific stage, and no evidence that interventions targeting stages do better than those which do not, leading to suggestions that a continuous variable of 'readiness' may be more useful than discrete stages of readiness (Sutton, 2007).
- The model does not allow for some people not knowing about the behaviour or the issue in question. This is likely when a rare or new illness or risk factor is being considered (such as HPV (human papillomavirus), or the 2020 coronavirus); or when the risk concerned is related to a relatively new behaviour, such as e-cigarette use. Lack of awareness is acknowledged in a less commonly employed model, the precaution Adoption Process model addressed below.
- As discussed previously, past behaviour is a powerful predictor of future behaviour. Godin et al. (2004) present a model which combines recent past behaviour with future exercise intentions to produce four 'clusters' of individuals with different attributes in terms of current behaviour and future intention. Attitudes and perceived behavioural control associated more strongly with membership of these staged clusters than with membership of the five stages of change that do not consider past behaviour. This suggests both intentions and current or recent behaviour could usefully be added to the TTM
- The model, as with many psychological models, insufficiently addresses the social aspects of much health behaviour (Marks et al., 2000).

Some of the proposed limitations of the TTM have been tested in intervention studies (see Chapter 6 ☛), where targeting the processes of change has not consistently resulted in the anticipated movement between stages. A systematic review of the findings of 37 controlled interventions studies provided limited support for stage appropriate interventions (Bridle et al., 2005), thus leading to calls for an end to TTM based interventions (e.g. Sutton, 2005; West, 2005); however, other studies do continue to provide support (Dijkstra et al., 2006; Hall and Rossi, 2008). The debate continues!

In a similar but less commonly tested model, the precaution adoption process model (PAPM) Weinstein and colleagues (Weinstein, 1988; Weinstein, Sandman and Blalock, 2008) describe seven stages and highlights important omissions in the TTM (Table 5.1). The major difference between this model and the TTM is that the PAPM gives greater consideration to the pre-action stages whereby in Stage 1 it is recognised that a person may have no knowledge/is basically 'unaware' of the threat to health posed by a certain risk behaviour or the absence of a protective behaviour, (e.g. unaware of HIV transmission routes) and in Stage 2, a person can be aware but 'unengaged', i.e. they believe that the levels at which they engage in it is insufficient to pose a threat to their health ('I know smoking causes various diseases, but I don't smoke enough for them to be a threat'). This is seen as 'optimistic bias' and led to Weinstein's development of the construct of unrealistic optimism (see earlier). Stage 3 is when people become engaged (similar to contemplation) where there considerations lead them either to Stage 4 which contains those who actively decide NOT to act or to Stage 5 where they decide to act (preparation and intention). The PAPM also theorises that those at stage 3 may be more open to information and persuasion than those with a definite stance (as in stage 4 or stage 5).

The PAPM has been tested less extensively than the TTM, although both models suffer from a lack of longitudinal testing. However, the PAPM does progress thinking to include the issue of awareness and pre decisional processes which has implications for the development of interventions. Deciding not to act is not the same as intending to and then not. Taking a conscious decision 'not to act' is one which has been found to be more resistant to change than simply being undecided, for example as reported in a Canadian study of HPV vaccine acceptability among Canadian parents (Tatar et al., 2019). Different styles of making decisions about using healthy nutrition or fitness e-health apps were reported from a large sample in the Konstanz Life Survey (König et al., 2018) – those who were 'unengaged' with adopting any such apps, used a more intuitive decision-making style whereas those who were engaged demonstrated a more deliberative decision-making style. The authors conclude that 'new user groups might be better reached by apps designed to address a more intuitive decision-making style' although this has yet to be tested.

**Table 5.1** Stages in the transtheoretical model and the precaution adoption process model

| Stage | Transtheoretical model | Precaution adoption process model |
|---|---|---|
| 1 | Pre-contemplation | Unaware of issue |
| 2 | Contemplation | Unengaged |
| 3 | Preparation | Engaged and considering whether to act |
| 4 | Action | Deciding not to act (and exit the model) |
| 5 | Maintenance | Deciding to act (and proceed to next stage) |
| 6 | | Action |
| 7 | | Maintenance |

## The health action process approach (HAPA)

The HAPA is a hybrid model having both 'static' and staged, temporal qualities. The HAPA fully embraces the issue of stages while also attempting to fill the 'intention–behaviour gap'. The HAPA highlights the role of post-motivational (or volitional) self-efficacy and action planning, factors not addressed by the TPB (Schwarzer, 1992; Schwarzer et al., 2008). The HAPA model has been influential because it suggests that the adoption, initiation and maintenance of health behaviour must be explicitly viewed as a process that consists of at least a pre-intentional motivation phase and a post-intentional volition phase (where a conscious choice or decision is made) which leads to the actual behaviour (Figure 5.3). Schwarzer (2001) further divided self-regulatory processes into sequences of planning, initiation, maintenance, relapse management and disengagement; however, the model has been best tested only for the first three of these.

### Motivation phase

As proposed in models such as the TPB, individuals form an intention to either adopt a precautionary measure (e.g. use a condom during sexual intercourse) or change risk behaviour (e.g. stop smoking) as a result of various attitudes, cognitions and social factors. The HAPA proposes

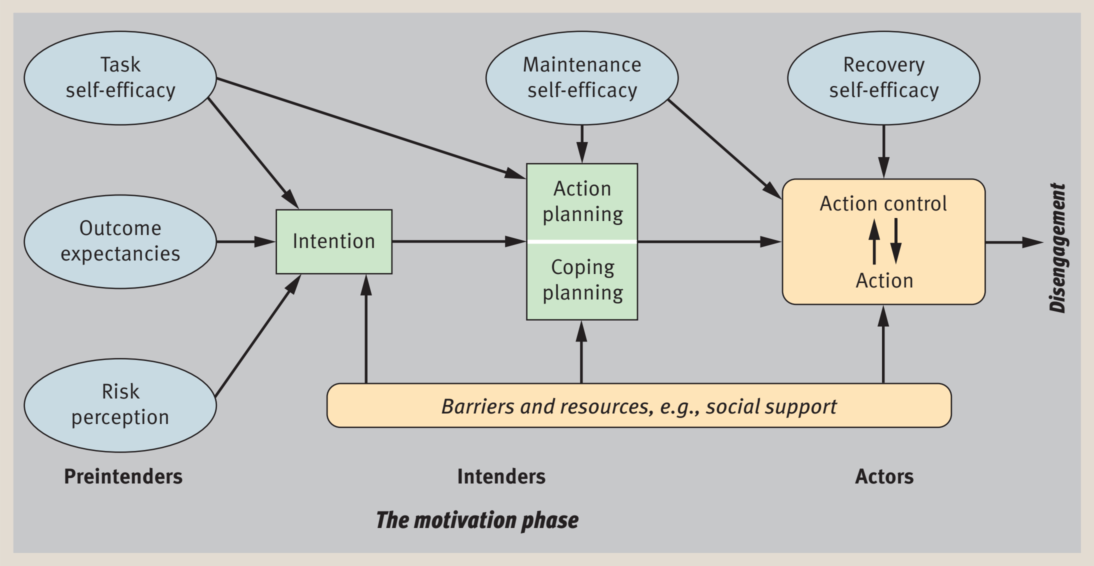

**Figure 5.3** The health action process approach model

*Source*: Schwarzer (1992).

that self-efficacy and outcome expectancies are important predictors of goal intention (akin to TPB perceived behavioural control). Perceptions of threat severity and personal susceptibility (perceived risk) are considered a distal influence on actual behaviour, playing a role only in the motivation phase (influencing outcome expectancies for example). Perceived threat is also considered to be of limited importance for some behaviours, such as fruit and vegetable intake (Schwarzer et al., 2007). It is theorised that outcome expectancies may precede self-efficacy (e.g. an individual probably thinks of the likely outcomes of their action before working out whether they can do what is required). Under conditions where individuals have no previous experience with the behaviour they are contemplating, the authors suggest that outcome expectancies may have a stronger influence on behaviour than efficacy beliefs.

Intention in the motivation phases is considered as a goal intention: for example, ‘I intend to stop smoking to become healthier’. Schwarzer also proposes *phase-specific self-efficacy* beliefs, consistent with Bandura’s findings (1997). Self-efficacy in the motivational stage is defined as ‘task/pre-action self-efficacy’: for example, ‘I can succeed in eating a healthy diet even if I have to change my lifestyle a bit’. At this stage, an individual needs to imagine successful outcomes and be confident in their ability to achieve them.

## Volition phase

Once an intention has been formed, the HAPA proposes that in order to turn intention into action, a conscious decision to act is made which involves planning. Such volitional processes are thought to be particularly important in the context of complex behaviours where multiple barriers might be anticipated. Fruit and vegetable consumption, for example, has perceived barriers including the need for high frequency to obtain benefits, cost, access, preparation, influence of others in the household etc. (e.g. Adriaanse et al., 2011a).

The HAPA incorporates Gollwitzer’s (1999; Gollwitzer and Sheeran, 2006) concept of implementation intentions (see above). These ‘when, where and how’ action plans are thought to turn the goal intention into a specific plan of action and at this stage a different kind of self-efficacy is required, that of initiative self-efficacy, whereby an individual believes that they are able to take the initiative when the planned circumstances arise. In other words the individual needs to believe that they can implement their plan when the morning of the planned diet arrives for example. Once the action has been initiated, the individual then needs to try to maintain the new, healthier behaviour. At this stage, coping (or maintenance) self-efficacy is required (e.g. ‘I will be able to keep going with this diet even if it is hard at first’). This form of self-efficacy describes a belief in one's ability to overcome barriers and temptations (such as being faced with a birthday celebration) and is akin to the self-regulatory processes described previously. Such beliefs enhance resilience, positive coping (such as drawing upon social support) and greater persistence. If, as many do, the individual gives in to temptation and relapses the model proposes that 'recovery self-efficacy' is necessary to get the individual back on track (Renner and Schwarzer, 2003).

Support for the role of self-efficacy at different stages in behaviour change was seen in a longitudinal study of breast self-examination behaviour among 418 women. Pre-actional self-efficacy and positive outcome expectancies (but not risk perception) were significant predictors of (goal) intention. Self-efficacy beliefs also predicted planning. In terms of actual BSE behaviour at follow-up 12–15 weeks later, planning was, as hypothesised, highly predictive, with maintenance and recovery self-efficacy also predicting greater behaviour frequency (Luszczynska and Schwarzer, 2003). Although it is perhaps surprising that risk perception regarding breast cancer was not predictive of intention nor behaviour, it may be that risk perceptions had influenced participants *before* they were assessed for the study, and therefore effects on the HAPA variables had passed. It is always hard in research to establish an absolute 'baseline' for measurement, and such results should not be taken as proof that risk perceptions are not important – the body of evidence would prove otherwise.

Further longitudinal evidence of the importance of phase-specific self-efficacy has been found among those undergoing cardiac rehabilitation and needing to adhere to a programme of exercise rehabilitation, where believing in one's ability to resume activity after failure or illness was a significant predictor of planning and of actual behaviour (Sniehotta et al., 2005b; Schwarzer et al., 2008). A recent meta-analysis of 95 studies using the HAPA (with 108 independent study samples, Zhang, Zhang, Schwarzer and Hagger, 2019) in relation to a range of different health behaviours confirmed the predictive role of both action and maintenance (motivational and volitional) self-efficacy and of outcome expectancy. The effects of outcome expectancies and action self-efficacy were, as hypothesised, mediated by intentions, and by action and coping planning.

Although effects were small-to-medium in size, such findings open up avenues to quite different intervention than those that address risk perceptions, generally found to be less significant in studies employing the HAPA. In addition, this meta-analysis points to different strength of effect depending on the behaviour studied for example, action self-efficacy had a larger effect on physical activity intentions and behaviour than it did on dietary change. Findings from studies using the HAPA have made a strong contribution to the field with volitional processes regarding action planning, coping planning and action control receiving much attention (e.g. Gollwitzer and Sheeran, 2006; Schwarzer and Luszczynska, 2008; Rhodes and de Bruijn, 2013). Significant empirical support has been obtained for what de Vries and colleagues (2006) describe as proximal post motivational determinants (e.g. action planning and control, goal setting, coping planning and control, implementation intentions).

## Limitations of the HAPA

The limitations of this model could be attributed to any of the preceding models and thus are raised only briefly here as they are discussed in the chapter conclusions and elsewhere. One recurring question is whether these models work better at explaining behaviour in some populations compared to others. With regards to the HAPA for example Renner et al. (2007) found that the components modelled the physical activity behaviour of middle-aged and older people better than it did that of younger people. As well as age, the findings of this study could also be culture specific as their sample was composed of South Koreans – another limitation to our models is that they are not always tested across multicultural populations. Finally, as with the previous models insufficient attention is given to non-conscious processes.

## The need to consider self-regulatory processes

While the models described in this chapter differ in some aspects they share a common goal – to aid understanding of correlates and predictors of health-related behaviours in order to better inform interventions. Increasingly, researchers consider sociocognitive models of health behaviour within a wider body of work concerning behavioural (and emotional) self-regulation, i.e. what we do deliberately, reflectively and consciously in order to achieve goals or desired outcomes (Hofmann et al., 2007; Hofmann et al., 2008 as cited in Sutton, 2010: 58;

**Photo 5.4** Preparing for healthy eating by making the purchases will increase the likelihood of action

*Source*: imagesource/123RF.

Hagger et al., 2009; Hagger, 2010). Self-regulation requires self-control, and individuals likely vary in that regard (Cameron and Leventhal, 2003)!

As we have described in this chapter, constructs such as 'action control', 'implementation intentions' and behavioural monitoring are highly pertinent. Research adopting a self-regulatory perspective in relation to health behaviour change includes that described by Hall and Fong (2007) as 'temporal self-regulation', where dynamic changes in thoughts and emotions are seen to influence, or 'regulate' our behaviour (see also the commentaries published in a Special Issue of *Health Psychology Review*, September 2010). It may be that for behaviours that require daily performance and maintenance, such as reduced fat intake or increased fruit and vegetable consumption, self-monitoring of one's behaviour against one's goals becomes increasingly important if relapse is to be avoided.

In many intervention studies it is clear that not all of the component parts of the models described in this chapter have been pursued in the manner the models intended. However certain aspects have emerged as critical and underpin many common interventional approaches. For example, the role played by information and awareness of a health threat (HBM, TTM (SoC)), cognitive and emotional components of attitudes towards the behaviour (TPB, PRIME), the perceived barriers and facilitators of behaviour, including social, environmental and cognitive behavioural barriers (such as perceived behavioural control, self-efficacy, skills, (TPB, PRIME, HAPA), and how these influence motivation and goals (TPB, PRIME, HAPA). Stage models in particular have contributed to understanding of the self-regulatory processes likely to facilitate change/move an individual closer to action.

A generalised model, the Information-Motivation-Behavioral skills (IMB) model (Fisher et al., 1994) adds information to individual capability, opportunity, motivation, the COM-B model proposed by Michie, which underpins many interventions and which is described in Chapter 6 ☛. The IMB basically considers that behaviour can be directly, or indirectly affected by the information a person has about the relevant behaviour and its consequences, the extent to which they are motivated to change the behaviour/consequences, and the extent to which the person possesses the necessary skills to do so. This brings together many of the key components we have discussed in this chapter. It is important however to remember that in these days of social media and online health and behaviour forums it is quite feasible that people receive the wrong or partially correct information, or fear arousing information where this is unnecessary.

Furthermore, a recent study comparing Irish and UK adults intentions to uptake COVID-19 vaccinations (Walsh et al., 2021) found that a sense of civic responsibility was a key predictor of vaccine acceptance along with peer influence, GP influence, vaccine attitudes, perceived risk, perceived severity, and flu vaccine behaviours among the Irish sample and in the UK sample also peer influence; civic responsibility; perceived risk; vaccination attitudes were predictive but in addition trust in authorities and perceived benefit. Trust in authorities, the influence of GPs, and sense of civic responsibility all point to a need to consider more fully the context in which individuals form their health beliefs and decisions around behaviour and behaviour change.

## SUMMARY

As shown in this chapter, many factors (proximal and distal) influence our behaviour and health behaviour and a wealth of research has sought to ascertain whether such models of health behaviour are useful. Certainly, our understanding of health behaviour has advanced following this research, but we are still far from being able to fully predict all behaviour (perhaps thankfully). As a consequence, interventions based on these models and their components vary in their success. Sociocognitive models like the HBM and the TPB highlight the importance of social and cognitive factors in predicting both intention to act and action, but did not facilitate understanding of the role played by emotion nor the processes of change. Stage models like the TTM, and the HAPA in contrast enabled further understanding of change by considering phase specific processes, volitional planning and action control processes. We have gone a long way towards filling the gap between intention and behaviour but it has also proven important to acknowledge that different factors determine behaviour initiation than behaviour change or behaviour maintenance (e.g. van Stralen et al., 2009). We do not yet fully understand the differential influences, but some factors emerge relatively consistently as predictors of change, such as perceived susceptibility and self-efficacy and, as such, carry intervention potential. Evidence of the efficacy of tailored interventions for different stages (which are more costly than a 'one size fits all' approach) is mixed however and interventions, such as described in Chapter 6 ☛ need to acknowledge this.

Furthermore, research has highlighted the particular challenges faced when trying to motivate change in habitual behaviour such as smoking, using models which rely on conscious processes and decision-making (Hofmann et al., 2008; Vangeli and West, 2008).

As noted above models and their components might 'work better' in some samples than do others. The prolific use of young and typically healthy student samples in much of the early behaviour change research, enabled theories to be tested and developed, however, the findings of such studies may not translate across to prediction of behaviour among older populations, less educated individuals, or to those leading less structured lives, such as the homeless drinker or drug user; or even to those who are attempting to change behaviour as a response to a life-threatening condition, such as dietary change following a heart attack, or physical activity among those with diabetes (e.g. Plotnikoff et al., 2010). Other social, environmental, cognitive and emotional factors are likely to play a role in these populations. Thankfully over the past decade in particular our predominantly cognitive models have increasingly addressed social and emotional influences on behaviour – our behaviour is influenced hugely by environmental context, by socio-economic resources, by culture and by laws, sanctions and habits . . . and by our mood. We have highlighted these at various points in most chapters, but also in detail in Chapters 1 and 2 ☛.

Therefore, whether reading research or planning some of your own, you should consider:

- The salience of potential predictors of behaviour may differ by behaviour (for example, subjective norm may be more important to smoking initiation than vitamin intake) and by characteristics of the sample (e.g. attitude to medicines may predict intention to adhere to medication in adults, but not in children, where adherence is more under parental control).
- The role of culture, ethnicity and religion may influence beliefs about health and preventive health. For example, an individual of the Muslim faith who drinks heavily will likely face very different emotional and normative pressures than someone of Christian faith.
- Cognitive models do not account very well for habitual behaviours driven more by non-conscious processes, nor for dependency-producing behaviours where physiological cues create impulses which may override rational thought.
- There may be bias in self-reports of illegal or socially undesireable behaviour or of behaviour perceived to be unconventional. For example, the incidence of teenage drug use as self-reported was significantly discrepant from that 'proven' in hair sample bioassays (Delaney-Black et al. 2010). Inncorporating objective measures into our research should be carried out where possible.

- We need to consider non-rational processes, such as impulsivity (Strack and Deutsch, 2004). People differ in the extent to which they can, or even wish to, control their impulses. When drunk, angry or tired, for example, we may reflect less on our behaviours or our decision-making, or be biased in the cues we attend to (Wiers and Hofmann, 2010). The influence of context on the shifting balance between reflection, attentional processes, impulse and behaviour is an important one.
- Finally, in considering the social, cognitive, emotional and behavioural processes that occur once a person has engaged in health behaviour change we will better inform interventions that seek to maximise maintenance of that change (see Chapters 6 and 7 ☛).

## Further reading

Conner, M. and Norman, P. (eds) (2015). *Predicting and Changing Health Behaviour: Research and Practice with Social Cognition Models*, 3rd edn. Buckingham: Open University Press.

A still useful text that provides comprehensive coverage of most of the models described in this chapter. A useful resource for sourcing measurement items for components of the models if you are designing a questionnaire.

Gardner, B., Rebar, A.L. and Lally, P. (2019). A matter of habit: Recognizing the multiple roles of habit in health behavior, *British Journal of Health Psychology*, 24: 241–247

How, and to what extent habit influences change processes in a given context for any given individual is a question health psychologists are interested in answering. This editorial provides a clear and succinct overview of the issues around habitual health behaviour and the challenges habit presents to models of behaviour change and to the development of optimal intervention.

Kompf J. (2020). Implementation intentions for exercise and physical activity: who do they work for? A systematic review. *Journal of Physical Activity & Health*, 17: 349–359.

A critical review of the effectiveness, or not, of implementation and planning-based interventions (see also Chapter 6 ☛).

# Chapter 6

# Changing behaviour: mechanisms and approaches

## Learning outcomes

By the end of this chapter, you should have an understanding of:

- the process of working with communities to determine the targets of public health programmes
- strategies used to increase motivation to change
- strategies used to change behaviour
- when and how best to use these interventions

## Health education doesn’t work!

Doctors have reported that many health education programmes fail to achieve any impact on behaviours including safer sex, smoking and attending hospital health clinics. Resorting to scare tactics made things even worse. There is an interesting assumption implicit in many government or health service strategies designed to change our behaviour – that if they tell us what to do, then we are likely to do it, especially if the message carries a slightly worrying health message. Yet, there is repeated evidence that simple factual or scary information does not work. One example of this failure can be found in the repeated government information campaigns about AIDS, the prevention of AIDS, and scary (indeed, terrifying) videos depicting death and hell as a consequence of enjoying unprotected sex broadcast in the UK in the late 1980s and 90s. Reported measures of condom use over this time revealed absolutely no change in response to any of these programmes. The public appeared utterly impervious to the potentially catastrophic consequences of AIDS and remained obstinately fixed in their old behaviours. Clearly, relevant information is necessary to instigate change, but many other factors contribute to the likelihood of change, and the simple repetition of health information (scary or otherwise), however accurate, is proven unlikely to significantly influence change.

## Chapter outline

This chapter outlines a range of strategies designed to motivate and support changes in health-related behaviours at both a whole population and individual level. It starts by examining the process through which health professionals can begin to consider what behavioural change may benefit whole communities or individuals within them, and how these can be supported by using or increasing resources from within that community. It then considers how to motivate change at an individual level and how to support the process of behavioural change.

The effectiveness of interventions discussed in this chapter are considered in Chapters 7 and 17 ☛. Chapter 7 ☛ examines their effectiveness in the context of reducing risk for disease among healthy individuals; Chapter 17 ☛ considers interventions in those who have already become ill. Finally, many of the theories and constructs referred to in this chapter have been covered in detail in Chapter 5 ☛, so it may be useful to refer back to this chapter at times.

# Developing public health interventions

Public health interventions are designed to change health behaviours within whole populations. The technology of behaviour change they use can therefore range from widely accessible approaches such as the mass media to smaller, more focused, interventions addressing individual needs. Despite their apparent differences, these approaches may have many commonalities. New skills, for example, may be taught using the mass media or working one-to-one with individuals, using the same principles of modelling and rewarding appropriate change. But before any intervention is developed, those involved need to determine which behaviours to address and how best to address them.

One of the best-known frameworks for supporting these sorts of decisions is known as the PRECEDE-PROCEED model (Green and Kreuter, 2005). It comprises two broad phases: preparing for change (PRECEDE) and intervening to change (PROCEED) The PRECEDE element identifies a range of psychosocial variables that could be the target of any intervention:

- Predisposing factors: knowledge, attitudes, beliefs, personal preferences, existing skills, and self-efficacy in relation to desired behaviour change.
- Enabling factors: characteristics of the environment that may facilitate behavioural change and the skills or resources required to achieve change. These include environmental factors including the availability and accessibility of resources or services, such as exercise facilities, cookery classes or crèches to allow young parents to exercise, that could facilitate behavioural change.
- Reinforcing factors: factors that reward or reinforce desired behaviour change, including social support, economic rewards, and social norms.

The model also takes into account any political, social, and environmental influences that may facilitate behaviour change, including changes in health, education, or social policy. The PRECEDE element comprises four sequential phases:

Phase 1: social diagnosis

- Planners gain an understanding of the health problems that affect the quality of life of a community and its members; their strengths, weaknesses, resources, and readiness to change. This may stem from community forums, focus groups, surveys, and/or interviews. If the model is fully implemented, local people are involved in the planning process and the planners are able to see the issues from the community's perspective.

Phase 2: epidemiological, behaviour, and environmental diagnosis

- Epidemiological assessment involves identification and assessment of health issue(s) specific to the community, and their related behavioural and environmental influences. These may involve a range of factors. Poor nutrition may be related to poor cooking skills, low nutritional knowledge, social norms that support the use of snacks and ready meals, and so on. Environmental diagnosis involves an analysis of social and physical environmental factors that could be linked to target behaviours. Dietary choice, for example, may be influenced by education or difficulties (physical or economic) in accessing healthy food. Interventions here may require policy changes.

Phase 3: educational and ecological diagnosis

- This phase involves prioritising and determining how to change any behaviours identified in phase 2, and identifying predisposing factors, enabling factors, and reinforcing factors of relevance. Consideration is also given to the likely impact of any behavioural change, the likelihood of any changes being made, and how acceptable to the target community any strategies of change are likely to be.

Phase 4 – administrative and policy diagnosis

- This administrative phase is designed to ensure that the programme is consistent with the policies of the organisation in which it is situated and which it wishes to address.

The PROCEED phase is just that: the implementation of the planned intervention with three elements of evaluation:

- *Process*: did the programme do what was intended?
- *Impact*: what impact did the intervention have on the target behaviours/outcomes?
- *Outcome*: what long-term effects on health were achieved?

### WHAT DO YOU THINK?

Before reading on, it may be interesting to consider how you would develop a public health programme and how you would evaluate it. Consider one 'simple' key health behaviour: maintaining COVID-19 safe behaviours within the general population. Governments across the world have struggled to manage these behaviours effectively. So, how would you facilitate engagement in these behaviours using a combination of large scale (such as the mass media), environmental, and individually based interventions? And how would you set about deciding whether you have actually achieved your goals? You may want to repeat this exercise after you have read the chapter and see if your ideas differ. These are not easy issues; if they were, our health problems would be resolved. So, good luck!

## Approaches to behavioural change

What the PRECEDE-PROCEED model does not consider in any detail are the optimal interventions to bring about change in each domain. How do we increase motivation, change beliefs and attitudes, encourage people to work towards desired goals, and so on? It is to these issues we now turn. Over the years, there have been a number of frameworks, intending to fill in the detail required by the PRECEDE-PROCEED approach. A document published by the UK Government Cabinet Office (The Institute for Government, 2010), for example, identified several factors that influence behaviour and may usefully form targets of any intervention, under the acronym of MINDSPACE. Their approach exemplifies the so-called nudge approach which involves small triggers designed to evoke small behavioural changes, and involves consideration of:

- *The 'Messenger'*: we are heavily influenced by who communicates information

- *Incentives*: we tend to work towards short term gains and to avoid significant losses
- *Norms*: we are strongly influenced by what others do or what we perceive them to do
- *Salience*: our attention is drawn to what is novel and seems relevant to us
- *Priming*: our acts are often influenced by subconscious cues in the wider environment
- *Affect*: our emotional associations and gain associated with behavioural change can powerfully shape our actions
- *Commitments*: we seek to be consistent with our public promises, and reciprocate acts
- *Ego*: we act in ways that make us feel better about ourselves

Applying these principles in practice involves what they termed the '4Es' policy framework:

- *Enable*: through interventions targeted at the environment in which behaviours are engaged, through the design of buildings, facilities, etc.
- *Encourage*: through a range of approaches including legislation, regulation, incentives to change, an information
- *Engage*: including working with individuals and communities
- *Exemplify*: through leading by example, policy consistency, and organisational learning

There are a number of more psychological frameworks, building on psychological theory that can be used to guide the development of interventions including the Information-Motivation-Behaviour model of Fisher et al. (2006) which identifies three primary constructs that influence behaviour change: information and knowledge about the behaviour, the degree of motivation to perform the behaviour; and having the behavioural skills necessary to perform the behaviour. However, the best-known model in the UK has been developed by Michie and colleagues (Michie et al., 2012). The core of their approach is what they term a 'behaviour system' incorporating three, interactive, elements: capability, opportunity, and motivation (collectively known as the 'COM-B system').

- *Capability* incorporates the individual's psychological and physical capacity to engage in the activity concerned. It includes the knowledge, skills and confidence to achieve change.
- *Opportunity* is defined as all the factors that lie outside the individual that enable, prompt, or inhibit change.
- *Motivation* involves the individual being able to make active choices in relation to engage in new behaviours and to have the energy to engage in them. Some motivation may result from 'cold' logical psychological processes; other motivation may be a consequence of 'hot' emotional processes. Increases in exercise, for example, may be linked to logical reasoning in terms of health benefits, but only enacted when also linked to the pleasure of exercising with friends.

Importantly for a psychological approach, the model does not take into account the 'level' of influence within the model and does not restrict its focus on obviously intra-individual factors. Opportunity, for example, may be influenced by a range of factors, many of which are environmental, financial, or social. Accordingly, the interventions implicated by the model need not necessarily be those targeted specifically, or exclusively, at the individual. Opportunity to exercise, for example, may be influenced by the availability and cost of gym membership, pollution-free and safe areas within a neighbourhood in which to exercise, or factors such as child-care provision to allow time to exercise as well as the traditional targets of psychological interventions such as beliefs, attitudes, and so on.

The framework is further delineated in what Michie (2011) termed the Behaviour Change Wheel. As you can see in Figure 6.1, the wheel has three movable parts, with the outer ring addressing a range of policy approaches to changing behaviour (which will be further addressed in the following chapter), and the middle ring addressing broad strategies of change that may be used across these various policy areas. Finally, the inner ring addresses the elements of the COMB-B system that can be influenced by each of the outer ring elements. Thus, for example, legislation (outer ring) may be used to influence the environment (middle ring) by requiring local councils to provide accessible exercise facilities, which in turn increases opportunity (as well as perhaps motivation and capability) of individuals engaging in exercise.

The wheel is still a rather broad-brush approach to behaviour change. Education and persuasion, for example, can be achieved using a wide range of approaches, likely to differ markedly in their effectiveness. Similarly, modelling and enablement cover a wide array of potential approaches and strategies. Each of these various approaches may then be determined by the theories

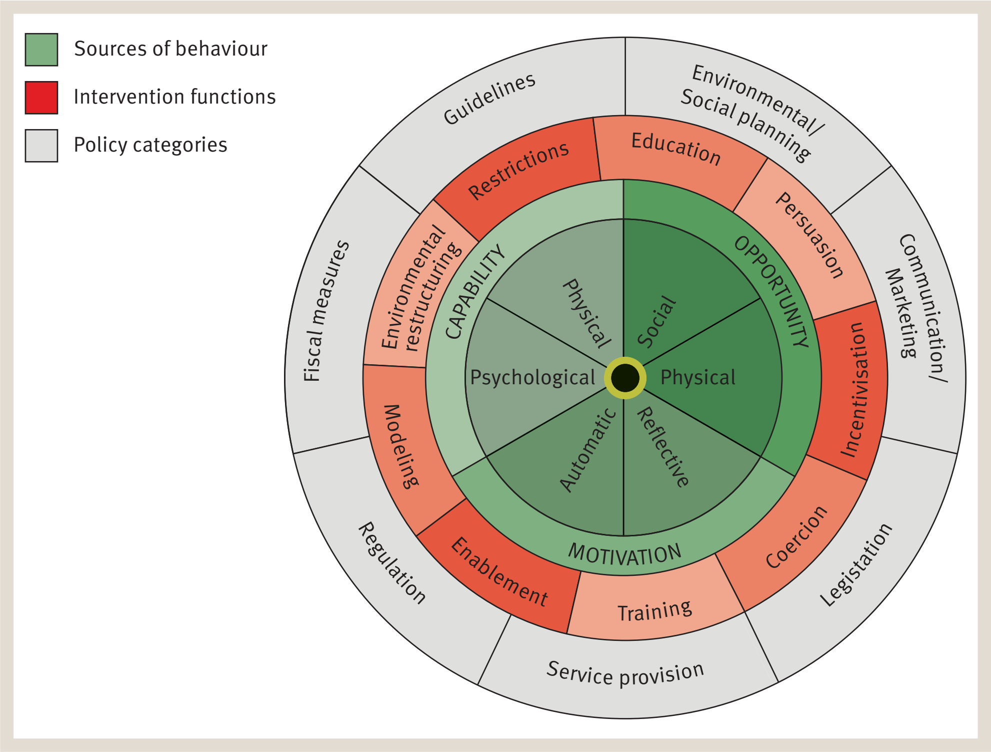

**Figure 6.1** The Behaviour Change Wheel

*Source*: Michie et al.

delineated in Chapter 5. As an example, Michie et al. (2012) broke down the optimal approach to encouraging smoking cessation into considerable detail. Alongside information provision, which should focus on the consequences of unhealthy behaviour in general and on the individual specifically, and information about normative behaviours and attitudes, they identified several other approaches to behavioural change.

Goal setting

- Establishing goals of behavioural change: ‘I will give up smoking after I finish this packet’;
- Establishing non-behavioural goals: ‘I will not get out of breath when I run for a bus’.

Action planning

- This is usually linked to goal setting and involves developing a plan through which to achieve goals. As a minimum, these should involve a ‘when statement’: ‘When I have the urge to smoke I will eat some fruit’.

Barrier planning/problem solving

- As part of a plan, consideration is also given to how to deal with challenges or barriers to the plan. These may form competing goals in specified situations. ‘I will not carry money, so if I am tempted to smoke, I will not be able to. I will ask my friends not to offer me a cigarette, however desperate I am.’

Set graded tasks

- Breaking a large target behaviour into smaller achievable tasks: ‘I will cut out five cigarettes each day for one week’.

Regular review of behavioural goals

- Review and reflection of behavioural goal achievement on a regular basis.

Regular review of outcome goals

- Review and reflection of outcome goal achievement on a regular basis.
- Regular rewards contingent on effort or progress towards behavioural targets and on successful behavioural change
- Includes self-reward (a treat for successfully cutting down smoking) or praise or rewards given by a health professional.

As you can see, the detail into which interventions are broken down and described is significant. This should allow researchers and practitioners to determine which elements of interventions are most useful, and those involved in developing interventions to ensure they include all possible active interventions. A combination of planning using the PRECEDE model combined with the use behavioural change approaches such as the COM-B and behaviour change wheel in combination with a range of theories of behaviour and behavioural change should ensure that future interventions, whether targeted at individuals or whole populations, will prove more effective than many of those used so far.

## Strategies of change: a theoretical perspective

Many public health interventions remain essentially atheoretical. Prestwich et al. (2014), for example, considered the theoretical underpinnings of published psychosocial interventions intended to increase levels of healthy eating and exercise. Only just over half (56 per cent) used theory to develop intervention techniques. The same indicator is likely to be much higher among unpublished, and un-researched interventions. Despite this agnosticism, as health psychologists, we should be turning to theory to guide our understanding of these processes.

One way of addressing this issue is to consider the psychological state of the individuals any programme hopes to influence. One helpful model from this perspective is the 'stages of change' (or trans-theoretical) model of Prochaska and di Clemente (1986), which we discuss in more detail in Chapter 5 ☛. This identified a series of five stages through which an individual may pass when considering change:

1. *P*re-contemplation: not considering change
2. *C*ontemplation: considering change but without thought about its exact nature or how it can be achieved
3. *P*reparation: planning how to achieve change
4. *C*hange: actively engaged in change
5. *M*aintenance or relapse: maintaining change (for longer than six months) or relapsing.

Prochaska and di Clemente noted the factors that may shift an individual from one stage to another (and they can move back and forth along the change continuum or even skip stages) can differ markedly. A smoker may shift from pre-contemplation to contemplation as a result of developing a chest infection, move to preparation and action after seeing a book on giving up smoking in the local library, and relapse after being tempted to smoke while out for a beer with friends. As a consequence, the model does not attempt to specify what these factors are; merely that they occur and that they can shift the individual from stage to stage.

Where the 'stages of change' approach has been particularly useful is from an intervention perspective in that it focuses consideration on what is the best type of intervention to conduct within each stage of change. The most obvious implication of the model is that there is little point in trying to show people how to achieve change if they are in the pre-contemplation or possibly the contemplation stage. Such individuals are unlikely to be sufficiently motivated to attempt change and will benefit little from being shown how to do so. By contrast, an individual in the planning or action stage may benefit from this type of approach, and less so from attempts to motivate change.

## Motivating change

### Information provision

One apparently simple approach to increasing motivation to change involves the provision of information. If individuals are unaware of the advantages of change, they are unlikely to be motivated to attempt to make change. The logic is clear. Unfortunately, while clear information may be of benefit when it is completely novel, does not contradict previous understandings of issues, is highly relevant to the individual, and is relatively easy to act on, health-related information rarely meets all these criteria. And even when it does, it may well not impact on behaviour. Early information films on the risk of HIV infection and how to counter it had remarkably little impact on sexual behaviour, even when the messages were absolutely novel, highly threatening, and the behaviour required to reduce risk of infection was (apparently) simple to implement (see discussion in the next chapter). Indeed, in the face of well publicised recent increases in sexually transmitted diseases (e.g. Huffington Post, 2013), consistent condom still remains relatively infrequent across the population, and particularly within some high-risk populations (e.g., Lan et al., 2017). Reasons for these failures are complex and involve social, psychological and situational factors. Many men and women used to unprotected sex can find negotiation of the use of condoms, as well as their actual use, complex and embarrassing. Risk may also increase at times of inebriation or other factors that reduce perceptions of risk or motivation to engage in safe behaviours (Lan et al., 2017). More complex cultural factors have included the positive embracing of risk in sexual relations and the meaning of condom use within a sexual relationship. Some HIV positive women, for example, have reported using a condom if having casual sex, but not with their regular partner, as this was considered to indicate a lack of trust and would result in a loss of pleasure for their partner.

Clearly, encouraging behaviour change in less critical circumstances, and when information is neither new nor dramatic (healthy eating, stop smoking) presents significant challenges. For this reason, a number of specific strategies have been used in attempts to influence motivation both at an individual and population level. Many informational approaches have identified the negative consequences of health damaging behaviour: damaged lungs, obesity and so on. But a wider set of influences may also include information that intends to increase motivation to change.

One key strategy is to provide information designed to increase motivation to engage in behavioural change. The NICE guidelines on behavioural change (NICE, 2014), for example, identified several ways of presenting information to increase the motivation of smokers to quit. They noted that key messages should influence:

- *Outcome expectancies*: Smoking causes people to die on average eight years earlier than the average.
- *Personal relevance*: If you were to stop smoking, you could add six years to your life, and be fitter over that time.
- *Positive attitude*: Life is good and worth living. Better to be fit as you get older than unable to engage in things you would like to do.
- *Self-efficacy*: You have managed to quit before. With some support there is no reason why you cannot sustain change now.
- *Descriptive norms*: Around 30 per cent of people of your age have successfully given up smoking.
- *Subjective norms*: Your wife and kids will appreciate it if you were to give up smoking.
- *Personal and moral norms*: Smoking is anti-social and you do not want your kids to start smoking.

These strategies clearly tap into a range of psychological theories, including social learning and social cognition theories such as the theory of planned behaviour, discussed in chapter 5. A more specific theory, specifically targeting strategies of attitudinal change, is known as the elaboration likelihood model (Petty and Cacioppo, 1986).

## The elaboration likelihood approach

Even the sophisticated informational approach considered above may be ignored or filtered out by potential recipients. The elaboration likelihood model (ELM; Petty and Cacioppo, 1986; see Figure 6.2) acknowledged these problems and considered how to work around them. The model suggests that attempts to motivate people who are uninterested in a particular issue using rational argument will not work; nor will they succeed if the arguments for change are weak. Only those individuals with a pre-existing interest in the issue are likely to attend to such process' messages if they are 'motivated to receive an argument' when:

- it is congruent with their pre-existing beliefs;
- it has personal relevance to them;
- recipients have the intellectual capacity to understand the message.

Such processing involves evaluation of arguments, assessment of conclusions, and their integration into

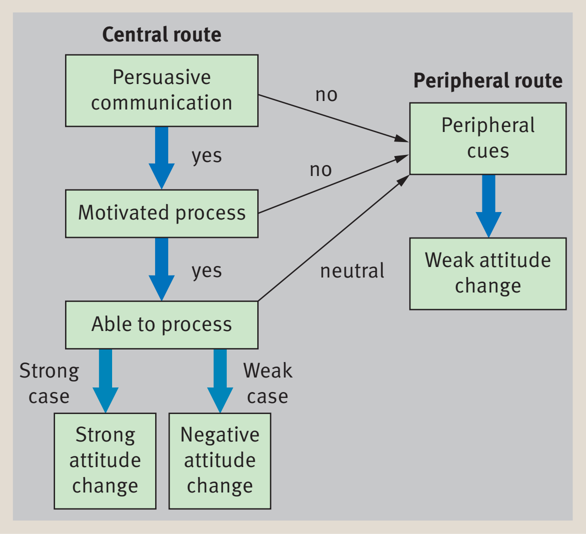

**Figure 6.2** The elaboration likelihood model of persuasive communication

existing belief structures. According to the ELM, any attitude change resulting from such deliberative processes is likely to be enduring and predictive of behaviour.

But what about those individuals who are less motivated to engage with logical arguments? According to the ELM, influence here is less reliable but still possible. The model suggests that this can be achieved through what it terms 'peripheral processing'. This is likely to occur when individuals:

- are not motivated to receive an argument;
- have low issue involvement;
- hold incongruent beliefs.

Peripheral processing involves maximising the credibility and attractiveness of the source of the message using indirect cues and information. Attempts, for example, to influence middle-aged women to take part in exercise may involve a technical message about health gains that can be achieved following exercise (the central route) and also include images associated with exercise that will appeal to the target audience, such as making friends while engaging in gentle exercise and wearing attractive clothes in the gym (the peripheral route). Similarly, the importance of a message can be emphasised by a senior person, such as a medical professor presenting information. More cautiously, Petty and Cacioppo noted that any attitude change fostered by the peripheral route may well be transient and not predictive of behaviour.

## The use of fear

A second potential approach to increasing the influence of both mass media and interpersonal communication is through the use of fear messages. This may partly involve ELM-based interventions. A number of UK television advertisements targeted at smokers provide good examples of this approach. These involved real people who had serious smoking-related illnesses – we were told that one person died soon after filming – talking about the adverse outcomes of their smoking. The film was black and white, and the images involved the people sitting in a chair against a very sparse background. The message was that smoking kills, and the peripheral cues associated with the image were downbeat and gloomy. It did not encourage the viewer to take up smoking!

Of course, one danger of this negative portrayal is that viewers may find it *too* depressing and simply disengage from the adverts – either mentally by thinking about something else, or physically by switching the television to another channel (see discussion of fear appeals in the next section). To avoid such an outcome, the PRECEDE model states it is necessary to develop media campaigns based on sound psychological theory and also to include a testing process, discussing the nature of the interventions with their target population – perhaps through the use of focus groups – to fine-tune the finished product.

Many health professionals consider fear arousal to be a key strategy to motivate change, and the approach has also proven popular among public health experts, politicians, and those involved in the mass media, including its recipients. Biener et al. (2000), for example, found the general public considered fear engendering advertisements to be more effective than humour. Despite this support, high levels of threat have proven relatively ineffective in engendering behavioural change.

Rogers' (1983) protection motivation theory provides one explanation for these findings. This suggests that individuals will respond to information in either an adaptive or maladaptive manner depending on their appraisal of both threat *and* their own ability to minimise that threat (their self-efficacy judgements). According to Rogers, an individual is most likely to behave in an adaptive manner in response to a fear-arousing health message if they have evidence that engaging in certain behaviours will reduce any threat and they believe they are capable of engaging in them.

This approach was further developed by Witte's (1992) extended parallel process model which states that individuals who are threatened will take one of two courses of action: danger control or fear control. Danger control involves reducing the threat, usually by actively focusing on solutions. Fear control seeks to reduce the perception of the risk, often by avoiding thinking about the threat. For danger control to be selected, a person needs to consider that an effective response is available (response efficacy) and that they are capable of engaging in this response (self-efficacy). If danger control is not selected, then fear control becomes the dominant coping strategy. Fear control, in this context, involves withdrawal from the message, not the health threat, as it is too overwhelming. People may turn the television off, try to avoid thinking about an issue, and so on. Any intervention which triggers fear control may make people even less likely to consider change than before, as their immediate response to the health threat becomes one of avoidance.

Both these theories suggest that the most persuasive messages are those that:

- arouse some degree of fear: ‘Unsafe sex increases your risk of getting HIV’;
- increase a sense of severity if no change is made: ‘HIV is a serious condition’;
- emphasise the ability of the individual to prevent the feared outcome (efficacy): ‘Here are some simple safer sex practices you can use to reduce your risk of getting HIV’.

## Information framing

A less threatening approach to the development of health messages involves ‘framing’ the message. Health messages can be framed in either positive (stressing positive outcomes associated with action) or negative terms (emphasising negative outcomes associated with failure to act). Smoking cessation, for example, can be framed as either the positive gain of being more able to exercise, looking and smelling better, or the negative effects of not dying of cancer or other lung diseases. The use of sunscreen can be influenced by messages that urge you to use sunscreen to maintain a healthy skin, or to reduce the risk of skin cancer. Negative framing often gets quite close to the fear arousal discussed in the previous section, which has struggled to prove effective.

## Motivational interviewing

One of the most effective forms of persuasion, most often used in one-to-one interventions, is known as motivational interviewing (Miller and Rollnick, 2012). Its goal is to increase an individual’s motivation to consider change; not to show them how to change. If the interview succeeds in motivating change, only then can any intervention proceed to considering ways of achieving it.

Motivational interviewing is designed to help people explore and resolve any ambivalence they may have about changing their behaviour. The approach assumes that when an individual is facing the need to change, they may have beliefs and attitudes that both support and counter change. Prior to the interview, thoughts that counter change probably predominate; or else the person would be actively considering or attempting to change. Nevertheless, the goal of the interview is to elicit both sets of beliefs and attitudes and to bring them into sharp focus (‘I know smoking does damage my health’, ‘I enjoy smoking’, and so on). This is thought to place the individual in a state of **cognitive dissonance** (Festinger, 1957), which is resolved by rejecting one set of beliefs in favour of the other. These may (or may not) favour behavioural change. If an individual decides to change their behaviour, the intervention then focuses on consideration of how to achieve change. If the individual still rejects the possibility of change, they will typically not continue in any programme of behavioural change.

The motivational interview is deliberately non-confrontational. Miller and Rollnick considered it to be a ‘philosophy of supporting individual change’ and not attempting to persuade an individual to go against their own wishes. Nevertheless, a few key strategies can be identified. In its original iteration (Miller and Rollnick, 2002), key questions in the interview were:

- What are some of the good things about your present behaviour?
- What are the not so good things about your present behaviour?

The first question is perhaps slightly surprising but important, as it acknowledges the individual is gaining something from their present behaviour. It is intended to reduce the potential for resistance to any discussion of change. Once the individual has considered each issue, both for and against change, these are summarised by the counsellor in a way that highlights the dissonance between the two sets of issues. Following this feedback, the individual is invited to consider their reaction to this information. Only if they express some interest in change should the interview then go on to consider how to change.

Since its original conception, the motivational interview process has been further developed (Miller and Rollnick, 2012) and now incorporates a strong element of planned behaviour change, much as promulgated by Egan in the next section. It has also developed a number of additional strategies of motivating change, which make it a more explicit process of persuasion. These include:

**cognitive dissonance**

a state of discomfort resulting from holding two sets of opposing beliefs; usually resolved by rejecting one set in favour of the other

Consideration of the disadvantages of the status quo:

- What worries you about your current situation?
- What makes you think that you need to do something about . . . ?
- What difficulties or hassles have you had in relation to . . . ?
- What is there about your . . . that you or other people might see as reasons for concern?
- What do you think will happen if you don't change anything?

Consideration of the advantages of change:

- How would you like for things to be different?
- What would be the good things about . . . ?
- What would you like your life to be like five years from now?
- If you could make this change immediately, by magic, how might things be better for you?
- What are the main reasons you see for making a change? What would be the advantages of making this change?

Evoking the intention to change:

- I can see that you're feeling stuck at the moment. What's going to have to change?
- How important is this to you? How much do you want to do this?
- Of the options I've mentioned, which one sounds like it fits you best?
- Never mind the 'how' for right now – what do you want to have happen?
- So, what do you intend to do?

Evoking optimism about change:

- What makes you think that if you did decide to make a change, you could do it?
- What do you think would work for you, if you decided to change?
- When else in your life have you made a significant change like this? How did you do it?
- How confident are you that you can make this change?
- What personal strengths do you have that will help you succeed?
- Who could offer you helpful support in making this change?

## Changing behaviour

Following the rubric of the stages of change model, if individuals are motivated to change their behaviour, then any intervention should focus on helping them *achieve* the changes they wish to make. This may not be easy. How does a busy working mother find time to exercise or cook healthily? How does an addicted smoker quit? Some changes, such as moving from full fat to semi-skimmed milk are easy to make. But more complex behaviours, embedded in busy and demanding lives, may be much more difficult to change even if we are motivated to do so. It is estimated, for example, that around 70 per cent of smokers have made at least one attempt to quit smoking over any one-year period. Simply exhorting such individuals to change is likely to be of little benefit. They have tried and failed.

The reasons for failures to change can be complex and lie both within and beyond the individual. They may be a result of fluctuating motivation, lack of knowledge of how to change, obstacles to change that may be difficult to overcome, and so on. For this reason, the best approaches to changing behaviour support the individual in negotiating these issues.

### Problem-solving approaches

Problem-focused interventions involve considering *how*, rather than *whether*, to change and are best suited to individuals who want to change their behaviour but need help working out how to do this. Perhaps the most clearly explicated problem-focused counselling approach has been developed by Egan (e.g. 2013). His approach to problem-focused counselling is complex in parts but has an elegantly simple basic framework. It emphasises the importance of appropriate analysis of the problem the individual is facing as a critical element of the counselling process. Only when this has been achieved can an appropriate solution to the problem be identified. A further element of Egan's approach is that the job of the counsellor is not to act as an expert solving the person's problems. Instead, their role is to mobilise the individual's own resources both to identify problems accurately and to arrive at strategies of solution. Counselling is problem-oriented. It is focused specifically on the issues at hand and in the 'here and now', and has three distinct phases:

1. *Problem exploration and clarification*: a detailed and thorough exploration of the problems an individual is facing: breaking 'global insolvable problems' into carefully defined soluble elements.

2. *Goal setting*: identifying how the individual would like things to be different. Setting clear, behaviourally defined, and achievable goals (or sub-goals).
3. *Facilitating action*: developing plans and strategies through which these goals can be achieved.

Some people may not need to work through each stage of the counselling process. Others may be able to work through all the phases in one session. Still others may require several counselling sessions. However, it is important to deal with each stage sequentially and thoroughly. Flitting from stage to stage serves only to confuse both the counsellor and the individual being counselled.

### Case history

Mrs T provides a good example of how the problem-solving approach may lead to issues and interventions far from those that might be expected. Mrs T took part in a regular screening clinic held at her local GP's surgery, where she was found to be obese and to have a raised serum cholesterol level. Following standard dietary advice, Mrs T agreed to a goal of losing two pounds a week over the following months. She was given a leaflet providing information about the fat and calorific content of a variety of foods and a leaflet describing a number of 'healthy' recipes.

On her follow-up visits, her cholesterol level and weight remained unchanged – so she was referred to a health psychologist to provide her with more help. The psychologist used the problem-focused approach of Egan. In the first session, she explored why Mrs T had not made use of the advice she had previously been given. Mrs T explained that she already knew which were 'healthy' and 'unhealthy' foods. Indeed, she had been on many diets before – without much success. Together, she and the psychologist began to explore why this was the case. At this point, a number of problems became apparent. One important issue was that she was not receiving support from her family, and in particular her two grown-up sons. Mrs T was the family cook, in a family that often demanded 'fry-ups'. She accepted this role but had difficulty in not nibbling the food as she cooked it. Although she actually ate quite small (and low-fat) meals, her nibbling while cooking significantly increased her calorie and cholesterol intake.

Mrs T's husband supported her attempts to lose weight and was prepared to change his diet to help her. However, her sons often demanded meals when they got back from the pub, late at night and often the worse for drink. The upshot of this was that Mrs T often started to cook late at night at the end of what may have been a successful day of dieting. She then nibbled high-calorie food while cooking. This had two outcomes. First, she increased her calorie input at a time when she did not need calories. Second, she sometimes catastrophised ('I've eaten so much, I may as well abandon my diet for today') and ate a full meal at this time. It also reduced her motivation to follow her diet the following day.

Once this specific problem had been identified, Mrs T set a goal of not cooking late night fry-ups for her sons. She decided that, in future if her sons wanted this, they could cook it themselves. Once the goal was established, Mrs T felt a little concerned about how her sons would react to her no longer cooking for them, so she and the psychologist explored ways in which she could set about telling them – and sticking to her resolution. She finally decided she would tell them in the coming week, explaining why she felt she could no longer cook for them at that time of night. She even rehearsed how she would say it. This she did, with some effect, as she did start to lose weight.

## IN THE SPOTLIGHT

The political and population response to COVID-19 highlights brings into stark relief many of the issues relevant to health behaviour change interventions. Despite high levels of infection, healthcare systems being overwhelmed, and millions of deaths worldwide, attempts at a governmental level to control the pandemic have been confused and politicised. In the USA, President Trump argued the use of masks was an infringement of human rights and encouraged attendance at what have been called 'super-spreader events'; election rallies where only a minority wore masks. Wearing a mask became highly politicised. Crudely put, Democrats encouraged their

*(continued)*

use; Republics decried their use. In the UK, lockdown measures were confused, seen as partisan (at one time some people argued they had largely been confined to labour voting areas in the North), often considered by critics as being too little too late, and frequently ignored. Decisions such as whether or not to close schools were delayed, confused and at times contradictory. Meanwhile, the numbers infected by covid-19 and dying from it rose inexorably. The clear health imperative was to prevent infection through lockdown: minimising contact with potentially infected individuals, reducing the rate of infection, and saving lives. The goal of politicians was to minimise costs, save the economy and jobs, and maintain the education of the next generation of children. Pity the poor politicians who eventually had to juggle these contradictory demands.

## Smoking cessation as a form of problem-solving

Although they may not explicitly state it, many behavioural change programmes have within them an element of problem identification and resolution. The example of smoking cessation can illustrate this point. Smoking is driven by two processes:

- a conditioned response to a variety of cues in the environment – picking up the telephone, having a cup of coffee, and so on – the so-called habit cigarette;
- a physiological need for nicotine – to top up levels of nicotine and prevent the onset of withdrawal symptoms.

Nicotine is an extremely powerful drug. It acts on the **acetylcholine** system in the central nervous system and mediates levels of attention and muscle activity throughout the body. Its activity is bi-phasic. Short, sharp inhalations increase activity in this system as the nicotine bonds with the acetylcholine receptors and activates the neurons – resulting in increased alertness. Long inhalations, by contrast, result in the nicotine remaining in the post-synaptic acetylcholine receptors, preventing further uptake of nicotine or acetylcholine by the receptors – leading to feelings of relaxation. Accordingly, when an individual stops smoking, they may have to deal with:

- the loss of a powerful means of altering mood and level of arousal/alertness;
- withdrawal symptoms as a consequence of a biological dependence on nicotine;
- the urge to smoke triggered by environmental cues.

acetylcholine

a neurotransmitter responsible for muscle activation and involved in attention and arousal

The best smoking cessation programmes address each of these issues. Following a ‘quit day’, most call for complete cessation of smoking, following which the individual may have to cope with varying degrees of urges to smoke as a result of withdrawal symptoms or encountering cues that previously were associated with smoking. Any withdrawal symptoms may take up to two or three weeks to subside and be at their worst in the first two to three days following cessation. Accordingly, there is an acute period of high risk for relapse following cessation which may be driven by the immediate psychological and physiological discomfort associated with quitting.

Many programmes prepare ex-smokers to cope with these problems. Each set of strategies involves a degree of problem solving, and uses strategies outlined in the COM-B process described earlier in the chapter, as the smoker has to identify both the particular problems they may face and individual solutions to those problems (see Table 6.1). The strategies may involve:

- coping with cues to smoking – this may involve avoiding them completely or working out ways of coping with temptation triggered by smoking cues;
- reducing the possibility of giving in to cravings should they occur;
- coping with any withdrawal symptoms.

One strategy for coping with any withdrawal symptoms involves the use of nicotine replacement therapy (NRT), either as a gum, spray, patch on the skin, or e-cigarette. The development of NRT was initially seen as a major breakthrough that would prevent the need for any psychological intervention to help people to stop

**Table 6.1** Some strategies that smokers may use to help them to cope in the period immediately following cessation

| Avoidant strategies | Coping strategies |
|---|---|
| Sit with non-smoking friends at coffee breaks | If you feel the urge to smoke, focus attention on things happening around you – not on your desire for a cigarette |
| Drink something different at coffee breaks – to break your routine and not light up automatically | Think distracting thoughts – count backwards in sevens from 100 |
| Go for a walk instead of smoking | Remember your reasons for stopping smoking – carry them on flashcards and look at them if this helps |
| Chew sugar-free gum or sweets at times you would normally smoke | Cognitive re-labelling: 'These horrible symptoms are signs of recovery.' |
| Move ashtrays out of sight | |
| Try to keep busy, so you won't have time to think of cigarettes | |
| Make it difficult to smoke | |
| Don't carry money – so you can't buy cigarettes | |
| Avoid passing the tobacconist where you usually buy your cigarettes | |

smoking. This has not proved to be the case. Indeed, most manufacturers of nicotine replacement products now recommend using a number of problem-solving strategies along with the NRT – a recommendation clearly supported by the outcome of clinical trials of their use.

## Implementing plans and intentions

A simpler, but potentially highly effective approach to changing behaviour, involves identifying and planning change of one key or series of related behaviours. According to Gollwitzer (1999), we often fail to translate goal intentions into goal attainment. This may occur for a number of reasons:

- *Failing to start*: the individual does not remember to start, they do not seize the opportunity to act, or they have second thoughts at the critical moment.
- *Becoming 'derailed' from goal striving*: the individual is derailed by enticing stimuli, they find it difficult to suppress habitual behavioural responses, or many be adversely affected by negative mood states or the expectation of negative mood if they implement change.

To overcome these obstacles, a relatively simple procedure known as implementation intentions may be utilised. This involves a so-called 'if-then' approach: '*If* I

**Photo 6.1** Choosing a quit date and ritually getting rid of all cigarettes can be a good start to stopping smoking.

*Source*: Rob Byron/Shutterstock.

find myself bored and hungry, *then* I will try to find something active to do.' The ideal, is that the action is specified in terms or when, where and how. Although simple, the premise of this approach is that this process will result in a mental association between representations of specified cues (feeling bored) and means of attaining goals (engaging in non-boring activities; not eating), which will become activated when the cue is encountered.

Developing appropriate implementations can be relatively simple in practice, particularly for one-off simple behaviours. Payaprom et al. (2011), for example, suggested the following implementation plan to increase uptake of flu vaccine among high-risk older adults: 'When I get an appointment letter to have the flu vaccine, I will go to the flu vaccine at . . . and I'm going to get there by . . . ' Other if-then links may be made as part of changing more complex behaviours: 'If I have an urge to smoke in the house I will play a game on the X-box to take my mind of it'; 'If I am offered a cigarette by a friend . . . ', and so on. Establishing these if-then associations may promote the initiation of goal striving behaviours, stabilise them over time, and shield the individual from alternatives and obstacles. Here are some typical implementation intentions, linked to potential problems they are trying to combat:

| | |
|---|---|
| ● Failing to get started | If it is 8 am on Friday, I will ride my bike to work. |
| ● Missing opportunities | As soon as I hear from the doctor, I will book my health check-up. |
| ● Initial reluctance | If it is Saturday 10 am, I will prepare five healthy meals to eat during the week. |
| ● Unwanted attention to distractors | If I start to think about snacking, I will focus on alternative things to do. |
| ● Stopping old habits | If I see the stairs, I will tell myself how good I will feel if I walk up the stairs – and do it. |

**RESEARCH FOCUS**

## Can implementation intentions change your brain?

Mcgrath, E., Armitage, C. J., Mckie, S. et al. (2020). Evidence that implementation intentions enhance cognitive training and reduce alcohol consumption in heavy drinkers: a randomized trial. *Annals of Behavioral Medicine,* 54: 391–401.

This study takes a relatively novel approach to reducing alcohol consumption, by targeting cognitive processes underpinning decisions related to drinking episodes, such as impulsivity, executive control, and attention. Studies targeting these processes have achieved significant, but relatively modest reductions in consumption. With this in mind, the present study aimed to find whether the addition of an implementation intention intervention including the use of 'if-then plans' would achieve additional benefit. In addition to measures of alcohol consumption, the study also investigated whether this intervention changed neurological functioning underpinning any behavioural change. It hypothesised that any increase in executive function would be accompanied by an increase in activity in the medial prefrontal cortex, and area of the brain associated with planning and behavioural control. This was explored by conducted functional MRI scans while participants completed two experimental tasks.

### Method

#### *Participants*

Volunteers, were recruited via advertising on posters and social media, were 34 people aged 18–65 years (18, women) who reporting regularly consuming more than 21 units of alcohol per week. (Government guidelines recommend a maximum of 14 units per week). Following a clinically diagnostic interview, potential participants were excluded if they had a history of alcohol abuse disorder, were prescribed or took non-prescribed psychotropic drugs except for cannabis (tested for in urine sample) and a history of neurological or neuroendocrine disorder.

### Measures

*Timeline Follow-Back (TLFB) assessment*: Alcohol consumption for 28 days prior to entry into the study and in the 28 days following the intervention was recorded through a detailed day by day focused interview using key dates and memory aids to identify total consumption over this period.

### Procedure

Two neurological tasks conducted in an MRI scanner formed both assessment and intervention.

*Imaging* was conducted using a Philips 3T MR scanner. Activity was measured in a number of brain regions: the precentral gyrus, superior temporal gyrus, nucleus accumbens, medial prefrontal cortex, amygdala, dorsolateral prefrontal cortex, anterior cingulate cortex, inferior frontal gyrus, hippocampus, insula, and middle temporal gyrus.

The experimental tasks were run on a laptop computer, with the screen view projected via a series of mirrors into participants' eyeline while in the scanner. Participants responded to the task conditions by pressing buttons on an MR-compatible button box using their index finger only. The experimental tasks were:

- *Alcohol Approach-Avoidance Task*: participants identified images as being either alcohol-related or not using an 'approach' or 'avoidance' paradigm, in which participants moved an image of a mannikin figure either toward or away from the images (of alcohol or tools) by pressing one of two buttons on a response pad. The key task comprised three blocks of 12 trials comprising a fixation cross, followed by 12 images in each category. When presented with images of alcohol, participants were expected to pull away from the image, and move towards images of tools. Feedback on whether they had given the correct response followed each trial.
- *Visual probe task*: participants viewed pairs of images followed by presentation of a cross at the top or bottom of the screen. Alcohol avoidance blocks comprised pairing an alcohol and water image, with the cross always appearing under the water. Control blocks consisted of images of tool and cosmetics. After each trial, participants indicated under which image the cross appeared, with immediate feedback as to their accuracy.

These tasks were conducted twice, with participants randomly assigned to a control or intervention between the two experimental phases: (i) *a control condition* in which participants read a statement explaining the need to focus attention away from the alcohol related images and towards the water images, and (ii) an *implementation intention intervention* in which they developed if-then plans to focus their attention away from alcohol-related images.

## Results

### Impact of implementation intentions on consumption

The mean level of alcohol consumption prior to the study was 42.5 units per week. Two analyses were conducted to assess the impact of the implementation intention intervention: changes in mean levels of consumption over the 28-day follow-up (reported as units per week), and changes in the percentage of participants categorised as 'heavy drinkers' (> 21 units per week). On the measure of units consumed, ANOVA revealed a significant time x condition interaction ($F(1, 31) = 4.72$, $p = 0.038$, $d = 0.81$.), with consumption falling significantly more in the implementation intentions condition (7.6 versus 1.2 unit reduction). In addition, Chi-squared analysis showed significant differences between the groups at 1 month follow-up on the measure of heavy drinking: (X2[1, N = 32] = 6.00, p = .014). The percentage of heavy drinkers fell from 16 per cent in both groups to 9 per cent in the implementation intentions condition and 15 per cent in the control condition.

### Cognitive performance

Reaction times on the visual probe task changed significantly over time, with participants showing significantly faster reaction times on alcohol-avoidance trials in comparison to control participants following the intervention (t[30] = −2.315, p = 0.028, d = 0.085). No between condition differences were following the control trials

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(t[30] = 1.479, p = 0.150, d = 0.58). Disappointingly, while task performance scores, measured as the number of 'correct' responses, significantly predicted subsequent changes in weekly consumption (b = –2.045, SE = 1.111, p = 0.036), they did not mediate the relationship between the use of implementation intentions and subsequent alcohol consumption.

No between group differences were found on the approach-avoidance task.

### *Influence on neural activity*

No differences in neural activity were found between the groups or over time.

## Discussion

This was an exciting study, which attempted to identify the neurological underpinnings of a simple, but clearly effective, psychological intervention. That the very simple intervention worked, and at a clinically meaningful level, attests to the potential impact of implementation intentions. More disappointingly, tying this gain into the cognitive or neurological consequences of engaging in this strategy proved more difficult. Nevertheless, exploration of links between a psychological intervention and fundamental processes underpinning its effect is exciting and something we should see more often.

## Modelling and practice

Problem-focused and implementation intention-based interventions can help individuals develop strategies of change and determine when such changes can be enacted. However, achieving change can still be difficult, particularly where an individual lacks the skills or confidence in their ability to make them. Egan himself noted that it may be necessary to teach people the skills to achieve any goals they have set or to change the social norms in which such behaviours occur.

One way to remedy these deficits is by learning skills from observation of others performing them: a process known as vicarious learning. Bandura's (2001) social cognitive theory suggests that both skills and confidence in the ability to change (self-efficacy) can be increased through a number of simple procedures, including observation of others performing relevant tasks, practice of tasks in a graded programme of skills development, and active persuasion. Bandura identifies three basic models of observational learning:

- *a live model*, which involves an actual individual demonstrating or acting out a behaviour
- *a verbal instructional model*, which involves descriptions and explanations of a behaviour
- *a symbolic model*, which involves real or fictional characters displaying behaviours in books, films, television programs, or online media

The effectiveness of learning from observation of others can be influenced by a number of factors. However, optimal learning and increases in self-efficacy are often achieved through observation of people similar to the learner succeeding in relevant tasks. This provides a 'coping model', which does not leave the observer feeling de-skilled or incapable of gaining the skills. Indeed, it gives them confidence they can achieve them ('If they can do it, so can I'). Complex skills can be taught through observation models learning skills over time and through various stages.

A further addition to problem-solving or implementation-based strategies involves the practice of new behaviours. Here, solutions to problems as well as the skills needed to achieve change can be worked out and taught in an educational programme, increasing both skills and self-efficacy. Cookery, purchasing and negotiating the use of condoms, the skills required to refuse a proffered cigarette, for example, can all be taught and practiced. Differing approaches can be planned, rehearsed, and feedback may be given within educational or counselling sessions in order to develop skills before their use in the 'real world'. Modelling change has the advantage that it can be done remotely, through the use of mass media and other large interventions, or at a more individual level.

## Cognitive interventions

The interventions so far considered can be thought of as behavioural interventions, in that they attempt to directly influence behaviour. They may also result in cognitive change: increasing an individual's confidence in their ability to make and maintain any lifestyle changes, and so on. But this is an indirect effect. By contrast, cognitive strategies attempt to change cognitions directly and in particular, those that drive an individual to engage in behaviours that may be harmful to their health or prevent them making appropriate behavioural changes. From a health psychology perspective, various categories of relevant cognitions have been identified, including attitudes towards the behaviour and relevant social norms (Ajzen, 1985), beliefs about the costs and benefits of disease prevention and behavioural change (Becker, 1974), self-efficacy expectations (Bandura, 2001) and beliefs about an illness or condition and the ability to manage it (Leventhal et al., 1984) (see Chapter 9 ☛).

The need to change cognitions is based on the premise that individuals may not have relevant information or have developed distorted or inappropriate beliefs about a relevant issue, and that changing these beliefs will result in more appropriate (and health-promoting) behaviour. The simplest form of intervention may involve the provision of appropriate education – particularly when an individual is facing a new health threat or is unaware of information that may encourage appropriate behavioural change. Such education is likely to be optimal if it targets factors known to influence health-related behaviours. It can educate individuals about the nature of their risk, show them how to change their behaviour, and so on. This approach has been considered earlier in the chapter.

More complex interventions may be required to change inappropriate beliefs that have been developed and reinforced over time. Beliefs that encourage substance use or abuse, for example, may include ‘I cannot cope with going to a party without a hit’ or ‘Drinking makes me a more sociable person’. At the beginning of a history of drug use, positive beliefs such as ‘It will be fun to get high’ may predominate. As the individual begins to rely on the drug to counteract feelings of distress, more dependent beliefs may predominate: ‘I need a drink to get me through the day’. Cognitive interventions may be of benefit where such thoughts interfere with any behavioural change. Key to any intervention is that the beliefs we hold about illnesses, our health, events that have happened or will happen in the future, and so on, are *hypothetical*. Some of these guesses may be correct; some may be wrong. In some cases, because maladaptive beliefs (‘I need a shot of whisky to get through this’) come readily to mind, they are taken as facts, and alternative thoughts (‘Well, I might be able to cope without’) are not considered. The role of cognitive therapy is to teach the individual to treat their beliefs as hypotheses and not facts, to try out alternative ways of looking at the situation and to have different responses to it based on these new ways of thinking (‘Well, I used to cope in this situation before without having a drink. Perhaps I can do the same this time’).

One way in which this can be achieved involves a process known as Socratic dialogue or guided discovery (Beck, 1976). In this, beliefs about particular issues are identified and questioned by the therapist in order to help the individual to identify distorted thinking patterns that are contributing to their problems. It encourages them to consider and evaluate different sources of information that provide evidence of the reality or unreality of the beliefs they hold. Once they can do this in the therapy session, they can be taught to identify and challenge these automatic thoughts in the real world and to replace thoughts that drive inappropriate behaviour with those that support more appropriate behaviour. An example of their use is provided by this extract from a session adapted from Beck et al. (1993) using a technique known as the downward arrow technique designed to question the very core of an individual’s beliefs – in this case their assumptions about their drinking.

**Health professional** You feel quite strongly that you need to be ‘relaxed’ by alcohol when you go to a party. What is your concern about being sober?

**John** I wouldn’t enjoy myself and I wouldn’t be much fun to be with.

**Health professional** What would be the implications of that?

**John** Well, people wouldn’t talk to me.

**Health professional** And what would be the consequence of that?

**John** I need to have people like me. My job depends on it. If I can’t entertain people at a party, then I’m no good at my job.

**Health professional** So, what happens if that is the case?

**John** Well, I guess I lose my job!

**Health professional** So, you lose your job because you didn’t get drunk at a party?

**John** Well, put like that, perhaps I was exaggerating things in my head.

Here, the downward arrow technique has been used both to identify some of the client’s core beliefs and to get them to reconsider the accuracy of those beliefs.

A second strategy is to set up homework tasks that directly challenge any inappropriate cognitive beliefs that individuals may hold. An example of this can be found in the case of the individual who believes that they cannot go to a party without drinking, and who may be set the homework task of trying to remain sober at a party – directly challenging their belief that they need to drink alcohol to be socially engaging (and the exaggerated ultimate belief that they will lose their job if they remain sober). Clearly, such challenges should be realistic. If a person attempts a task that is too hard and fails to achieve it, this may maintain or even strengthen the pre-existing beliefs. Accordingly, they have to be chosen with care and mutually agreed by both the individual concerned and the therapist. However, success in these tasks can bring about long-term cognitive and behavioural changes.

## Changing the environment

Almost all the interventions considered so far involve attempts to change the behaviour of individuals by directly interacting with their target audiences. However, health behaviours occur in a social and economic context; factors highlighted by the COM-B and behaviour change wheel. Individual dietary choice, for example, may be influenced by children being unwilling to eat lots of vegetables, partners not wishing to be meat-free, or a 'sugar tax' making high sugar products more expensive. Similarly, the level of exercise we can realistically engage in may be determined by our economic situation: can we afford gym membership, how long is our working week, and so on? It may also be moderated by the environment in which we live. Cycling in inner London, for example, may be a very different experience to cycling in the countryside; people may feel cautious about jogging close to busy roads with poor street lighting, and so on.

Because of the wide number of people affected by these issues, the social, economic, and environmental constraints on behavioural change may become targets for change at a local or policy level. The health belief model (Becker et al., 1977) (see Chapter 5 ☛) provides a simple guide to key environmental factors that can be influenced in order to encourage behavioural change. In particular, the model suggests that an environment that encourages healthy behaviour should:

- provide cues to engage in healthy behaviours or remove cues to unhealthy behaviour, e.g., signs reminding people to use the stairs, nutritional information on food packaging, removal of cigarette advertising from shops.
- minimise the costs and barriers associated with engaging in healthy behaviours, e.g., increasing the number of public recreation areas, cheap gym membership, building safe cycle paths, selling healthy food close to centres of economic deprivation.
- maximise the costs of engaging in health-damaging behaviour. e.g., increasing taxation of alcohol and cigarettes, not allowing smoking in public places, increasing the geographical distance between alcohol outlets.

Environmental strategies are widely used by governments, both national and local, to influence behaviour and are central to the PRECEDE model. A number of

**Photo 6.2** Cycling can be fun and healthy, but only in a safe and pollution free environment.

*Source*: Cathy Yeulet/123RF.

projects, under the rubric of the 'Healthy Cities movement' (World Health Organization, 2013), for example, have attempted to design city environments in ways that promote the mental and physical health of their inhabitants. The movement initially involved cities in industrialised countries but is now expanding to include cities in industrialising countries such as Bangladesh, Tanzania, Nicaragua and Pakistan. To be a member of the movement, cities have to develop a city health profile and involve citizen and community groups. Priorities for action include attempts to reduce health inequalities as a result of socio-economic factors, traffic control, tobacco control, and care of the elderly and those with mental health problems (Kickbusch, 2003). The most recent goals of the European Healthy Cities Network (WHO 2013; p 3) included:

- promoting action to put health high on the social and political agenda of cities
- promoting policies and action for health and sustainable development at the local level emphasising addressing the determinants of health, equity in health and the principles of the European policies Health for All and Health 2020
- promoting intersectoral and participatory governance for health, health and equity in all local policies and integrated planning for health
- generating policy and practice expertise, good evidence, knowledge and methods that can be used to promote health in all cities in the European Region
- promoting solidarity, cooperation and working links between European cities and networks of local authorities and partnerships with agencies concerned with urban issues

The complexity and rather abstract nature of these goals means they often *remain* goals and can be difficult to achieve or measure in a reliable manner. Nevertheless, the health cities movement provides an aspirational target for all cities.

## Spreading the word

A key social approach that has been used to disseminate new behaviours through the general population involves the use of individuals or groups within the population to actively promote any targeted changes, such as healthy eating, smoking cessation, and so on. It is based on a theory of the spread of new behaviours through society known as 'diffusion of innovations' (Rogers, 1983). In this, Rogers segmented the population in terms of their responses to innovation and their influence on the behaviour of others:

- *Innovators*: a small group of individuals, usually of high status. They seek out and gain ideas from a wide range of sources and are willing and able to test out new ideas gained from them. This group is relatively isolated from the 'mainstream'. However, they bring innovations to a group with wider links to the general population and with wider influence: early adopters.
- *Early adopters*: this larger group of people has a wider sphere of influence than innovators. They are often described as 'opinion leaders'. Potential adopters look to this group for information about an innovation, and they serve as role models for the wider population. Adoption of an innovation by this group is crucial to its adoption by the wider population.
- *Early majority*: this group adopts ideas reasonably early but does not have the power to influence the wider population.
- *Late majority*: these people adopt the innovation only after adopting by the early majority. They are a fairly cautious group and are only likely to adopt an innovation after it has been well tested by the previous groups.
- *Laggards*: this group of people are the last to adopt, or may never adopt, an innovation.

Rogers also noted a number of characteristics of any innovation that may influence its likely uptake by each group:

- Its advantage over other behaviours: the bigger the advantage the more likely it is to be adopted.
- Its compatibility with the values and norms of the social system it is trying to influence. If the innovation is too radical it will be rejected.
- Ease of uptake. If the innovation is easy to adopt, it is more likely to be adopted than if it is difficult to understand or engage in.
- Evidence of effectiveness. The more any effectiveness can be seen, the more likely it is to be adopted.

The model has a number of implications for the active diffusion of health enhancing behaviours by any public health intervention. It suggests key target groups that may be addressed in any public health information intervention. Early adopters, for example, may usefully be identified and targeted in any advertising of an innovation. They may also become actively involved in an intervention. Interventions discussed in the next chapter, for example, have actively recruited gay men of some standing in their local community to lead interventions designed to increase condom use among their peers.

## SUMMARY

1. The PRECEDE-PROCEED model provides a strong framework for the development of public health programmes. Key stages to their development including social diagnosis; epidemiological, behaviour, and environmental diagnosis; educational and ecological diagnosis; and programme implementation.
2. The COM-B and similar approaches provide a clear framework and links to relevant specific strategies in order to promote factors that influence change at all psycho-social and economic levels.
3. A number of approaches can be used to motivate behavioural change:
   (a) Information provision: ideally based round theoretically driven models of behavioural change and guidelines such as those developed by NICE.
   (b) The central and peripheral routes of the elaboration likelihood model
   (c) Appropriate informational framing: based on 'test' studies to identify the optimal framing for a particular intervention.
   (d) Motivational interviewing

   Similarly, a number of approaches can be used to change behaviour:
   - Problem-solving approaches
   - Implementation plans
   - Modelling and practice
   - Cognitive interventions

   A third approach to changing behaviour involves adopting the environment to facilitate or reward behavioural change and to inhibit engagement in health damaging behaviours.
4. Some change may filter through society in a natural way known as 'diffusion of innovation'. This process may be facilitated through the use of early adopters or opinion leaders as advocates of appropriate behavioural change.

## Further reading

http://www.nice.org.uk/Guidance/PH49/chapter/glossary#individual-level-behaviour-change-interventions

A range of internet links to the NICE guidelines on behaviour change, behaviour change competency frameworks, brief interventions, and much much more.

Michie, S., Carey, R.N., Johnston, M. et al. (2018). From theory-inspired to theory-based interventions: a protocol for developing and testing a methodology for linking behaviour change techniques to theoretical mechanisms of action. *Annals of Behavioral Medicine*, 52: 501–512.

Whittal, A., Atkins, L. and Herber, O.R. (2020). What the guide does not tell you: reflections on and lessons learned from applying the COM-B behavior model for designing real life interventions. *Translational Behavioral Medicine*, ibaa116.

An interesting consideration of some of the limitations of the COM-B model when applied in real life settings.

Miller W.R. and Rollnick S. (2012). Motivational Interviewing, Third Edition: Helping People Change (Applications of Motivational Interviewing). Guilford Press.

The latest iteration of the classic text on motivational interviewing.

Kompf J. (2020). Implementation intentions for exercise and physical activity: who do they work for? A systematic review. *Journal of Physical Activity & Health*, 17: 349–359.

A recent critical consideration of the state of the art of implementation and planning-based interventions.

Ahmed, S., Swaine, B., Milot, M. et al. (2017). Creating an inclusive mall environment with the PRECEDE-PROCEED model: a living lab case study. *Disability and Rehabilitation*, 39: 2198–2206.

A nice example of the use of the PRECEDE-PROCEED model in an important issue facing much of the population.

## YouTube

https://www.youtube.com/watch?v=bTRRNWrwRCo

A nice BMJ educational role play showing how motivational interviewing techniques can be used to diffuse difficult confrontations in medical consultations and encourage appropriate change

https://www.youtube.com/watch?v=4GzrNxPx1fg

Susan Michie talking about how to change behaviour

https://www.youtube.com/watch?v=uhMipNkHF9M

What better than to have a nice explanation of the COM-B from a trainee health psychologist, Carl Bryce from Manchester, which gets rave reviews?

https://www.youtube.com/watch?v=4CwrQxwxcWo

Chris Armitage, another leading UK health psychologist talks about issues of motivating behaviour change, including implementations. It's quite long and it's a talk given to professional health psychologists, but it has much of value.

WEB

Visit the website at **go.pearson.com/uk/he/resources** for additional resources to help you with your study.

# Chapter 7

# Preventing health problems

## Learning outcomes

**By the end of the chapter you should have an understanding of the effectiveness of the following approaches to changing health damaging behaviours:**

- individually based interventions including: risk factor screening programmes, motivational interview-based interventions, and problem-focused approaches
- using the mass media, including information framing, population targeting and the use of fear
- environmental interventions, including increasing cues to action, minimising the costs of healthy behaviour and increasing the costs of unhealthy behaviour
- public health programmes focusing on reducing risk for coronary heart disease and increasing safer sex
- worksite public health
- school-based interventions
- using new technologies

## An apple a day keeps the doctor away

Well, there is no evidence that eating one apple a day will provide any health advantage: although eating five portions of vegetables and fruit may. But the point of the title addresses a key issue in modern healthcare. In their report, *The Growing Danger of Non-Communicable Diseases: Acting Now to Reverse Course*, the World Bank (of all institutions!) concluded that Africa, Eastern Europe, and Asia face alarming increases in chronic disease levels as a consequence of poor lifestyle and suggests that if left unchecked these prevalence rates could increase from an already high 51 per cent to an alarming 72 per cent of all deaths. More than a third of these deaths will be preventable through appropriate changes in lifestyle. Western European countries, meanwhile, cannot afford to relax. The cost of caring for people with diabetes (1 and 2) absorbs 10 per cent of the NHS budget, with present estimates of £14 billion a year in England and Wales being spent on treating diabetes and its complications (Diabetes UK). Lifestyle related diseases, and in particular, type 2 diabetes and various manifestations of coronary heart disease and hypertension carry a massive financial toll as well as a personal one. Lowering these costs can only be achieved by significant lifestyle change among apparently healthy individuals.

## Chapter outline

**The previous chapter identified a number of strategies of behavioural change that can be used in interventions designed to prevent the onset of disease. This chapter examines the effectiveness of a range of interventions designed to reduce the health risk associated with health damaging behaviours such as smoking, poor diet, and low levels of exercise. It considers interventions that involve working directly with individuals and also those that target whole populations. This chapter also considers the anxiety that may be associated with some risk change programmes and how this can be addressed within the context of such programmes.**

# Working with individuals

## Providing health information

Even minimal advice to engage in healthier behaviours can be of benefit, particularly when coming from high status healthcare providers. Stead et al.'s (2008) review of relevant literature, for example, found that smoking cessation rates with no intervention were around 2 to 3 per cent each year and that advice to stop smoking by a doctor could increase them by an additional 1 to 3 per cent. Although a relatively small difference, if considered over the potentially thousands of smokers who could receive such advice the health impact of this approach could be significant, at minimal financial and time cost to the healthcare provider. Of note also, are the findings of Gilpin et al. (1993) who found that the first instance of advice was the most important determinant of quitting. Giving advice in further sessions did not result in further quit attempts.

Of course, this type of intervention only works if physicians actually provide the impetus to quit smoking; but this may not always be the case. This was certainly the finding of Unrod et al. (2007) who found that most of their sample of primary care doctors neither actively encouraged their patients to stop smoking nor followed simple guidelines on how this may be achieved. However, when these doctors were given specific training in smoking cessation techniques and used a one-page leaflet suggesting personalised strategies of how to stop smoking with their patients, they found abstinence rates of 12 per cent among the intervention group and 8 per cent among those who received standard advice to quit.

One more complex, but relatively common, intervention in primary care settings has involved screening individuals for risk of disease and giving information and advice on the need to change any identified risk factors. The most common context in which this approach has been adopted involves screening for risk of coronary heart disease (CHD) as a consequence of high cholesterol, blood pressure, or behavioural risk factors such as smoking or low levels of exercise.

Typical screening programmes invite adults (often now within pre-determined age ranges) to attend a 'health check' conducted by a nurse. This typically involves an interview to identify risk behaviours, and measures of blood pressure and cholesterol levels. Where appropriate, participants are advised to stop smoking, eat a low-cholesterol diet and/or increase their exercise levels, or receive medical treatment for hypertension and high cholesterol levels. Unfortunately, despite the apparent simplicity and directness of this approach, evidence of its effectiveness has proven surprisingly equivocal, with some studies providing evidence of small and possibly marginal behavioural changes, but few (e.g. Finkelstein, Khavjou and Will, 2006) providing strong evidence of effectiveness. Perhaps the final word on this issue lies within the results of a meta-analysis on data from 55 studies and over 139,000 participants conducted by Ebrahim et al. (2011) which concluded that the risks of having a cardiac event were identical for those who did or did not go through a CHD prevention screening programme.

Even extending support or increasing the sophistication of interventions appears to have only modest long-term benefit. Steptoe et al. (1999), for example, adjusted their intervention to suit the stage of change (see Chapter 6 ☛) of patients found to have risk factors involving regular cigarette smoking, high cholesterol levels, and high **body mass index (BMI)** combined with low physical activity. Practice nurses provided brief behavioural counselling using elements of motivational interviews for those who were in pre-contemplation and developed strategies of change for participants who were considering the possibility of change. Compared to no intervention, some benefits were achieved, but these were limited to modest, and clinically questionable, reductions in self-report dietary fat intake and the number of cigarettes smoked per day and increased self-report exercise at 4- and 12-month follow-up assessments.

As the emphasis on CHD screening programmes has lessened, research has begun to focus on attempts to prevent type 2 diabetes (see Chapter 8 ☛); a condition linked to the same behaviours as those leading to CHD. It can be detected in its pre-diabetic stage, before the onset of irreversible type 2 diabetes (see Chapter 8 ☛). Accordingly, some have argued that screening programmes similar to those associated with CHD may be of value: although given the disappointing findings so far considered, this may be an optimistic view. Indeed, the issues facing such programmes is that they frequently encounter and try to influence long-standing health damaging behaviours that may be difficult to change. The challenge, for example, to an obese individual starting to exercise in late middle age is clearly greater than that for younger, less overweight individuals. The question is therefore, does identification of risk (plus some modest support in behavioural change) facilitate sufficient long-term behaviour change to improve health?

As with CHD-risk factor screening, such programmes typically involved nurse-led interventions. In one such study (Coppell et al., 2017), based around education and monitoring of healthy eating, nurses and participants met on four occasions over a period of six months. The intervention provided a modest benefit on measures of weight loss and more marginal (and statistically insignificant) gains on measures of BMI, waist circumference and a long-term marker of blood sugar levels (*HbA1c*) (see Chapter 8 ☛) compared to usual care. This finding appears typical, with a meta-analysis by Roberts et al. (2017) concluding that there was a likely health benefit from such programmes, but that those which were most effective were also probably too complex and costly to be implemented in most healthcare systems.

One consequence of these modest outcomes has been to focus on strategies for enhancing behavioural change during this type of screening through the use of additional 'motivators'. One interesting approach involves the identification of genetic markers of risk for disease. But even this does not appear to be a powerful motivator. Hollands et al. (2016), for example, examined the impact of providing DNA-based disease risk estimates on subsequent health behaviour change. Their meta-analysis of data from 18 studies involving smoking cessation, dietary change, and exercise failed to find convincing evidence that provision of genetic risk for disease had any impact on any of these behaviours, related behaviours such as alcohol use, or even attendance at screening or behavioural change support groups.

## Motivating change

A more sophisticated approach to facilitating behavioural change among people with low motivation or in the pre-contemplation stage of change, involves the use of motivational interviewing (see Chapter 6 ☛). This approach was initially used to help people who presented with substance misuse problems but more recently has been used with a range of other behaviours. In the context of smoking, for example, Lai et al.'s (2010) meta-analysis comparing the effectiveness of motivational interviewing against brief advice revealed a 25 per cent higher quit rate among smokers receiving this intervention. Interestingly, the status of the health professional involved also influenced outcomes. The approach was most beneficial when delivered by primary care physicians, who achieved a three times higher quit rate following the use of motivational interviewing than simple advice or no intervention.

body mass index

a measure of weight in relation to height; allows a calculation of how heavy an individual is 'for their height' and mass determines whether an individual is over or under weight

Addressing other health behaviours, consumption of fruit and vegetables and exercise levels among older adults, Campbell et al. (2009) examined the effectiveness of either written information or information combined with a brief motivational telephone contact in two groups: people who had survived cancer and a group with no evidence of disease. They found the combined intervention was more effective than the simple provision of information in facilitating changes in diet, but only in the latter group; perhaps because those in the cancer survivor group likely to respond to this type of intervention had already made appropriate changes. The intervention had no impact on exercise levels. Dawson et al. (2014) also found limited benefits of a one-off motivational interview in a very different target group. In their study, children aged 4-8 years took part in a health screening programme following which their parents received feedback on the health consequences of their child's weight using a simple 'traffic light' visual aid or a motivational interview designed to encourage their participation in a family-based weight loss programme for their child. Both interventions were equally, if modestly, effective.

The relatively modest gains reported in these studies may perhaps be attributed to a failure to target appropriate participants. Neither intervention targeted individuals identified as having low levels of motivation; an issue common to many other trials that have had equally unsuccessful interventions (e.g. Moss et al., 2017). This issue is highlighted by the findings of Carels et al. (2007) who employed motivational interviews only with participants on a weight loss programme who failed to lose weight following standard behavioural counselling. In comparison to those struggling to lose weight who did not receive motivational interviewing, this group achieved greater weight loss and engaged in more exercise.

Motivational interviewing is perhaps most effective when integrated within more complex programmes of change. Caire-Juvera et al. (2019), for example, compared nutritional counselling against nutritional counselling combined with a motivational interview, with the latter achieving more change. A meta-analysis of ten similar trials conducted by Barrett et al. (2018) found that the addition of motivational interviewing to cognitive behavioural interventions led to additional, but modest, gains in physical activity and weight loss.

## Case history

A more personal account of the benefits of motivational interviewing in an unlikely context can be found in a one-off engagement with a smoker experienced by PB early in his career as a health psychologist. He was asked to see a smoker, JB, who had refused to give up smoking despite several increasingly insistent requests by his cardiologist for him to quit. He was experiencing significant health problems because of his smoking, the most critical of which were significant reductions in the diameter of the arteries supplying blood to his lower legs due to widespread atheroma. Their diameter was so reduced that when he walked, he was unable to get enough blood to the muscles in his lower legs and he experienced **ischaemic pain** in his calves. He was also experiencing mild angina due to similar processes in the cardiac arteries (see Chapter 8 ☛). Continued smoking, it was feared, would result in his need to have his lower legs amputated and a myocardial infarction (see Chapter 8 ☛).

PB was asked to see him in order to persuade him to stop smoking. This meeting was well before motivational interviewing was well known. Nevertheless, in somewhat of a panic (how do you persuade people to stop smoking when they don't want to?), he simply asked JB why, given the number of people who had asked him to stop smoking, he continued to do so. This question, which neatly fits the first of the original motivational interview questions of 'what are the good things . . . ' elicited a somewhat surprising response. JB was somewhat startled by the question and was very responsive to it. Rather than adopt a defensive response to yet another attempt at persuasion, he immediately began to ask himself this question, and concluded that he actually *did* want to stop smoking, but was frightened that he was unable to do so, as several previous attempts had ended in failure. This revelation shifted the atmosphere of the meeting to one of consideration of how to stop smoking, and application of strategies of change similar to those described later in the Chapter: with a highly successful outcome.

**ischaemic pain**
pain due to lack of blood supply to the muscles

## Planning change

While complex problem-solving change approaches (see Chapter 6 ☛) may be of value, recent developments have indicated that a cut-down version of this approach may also be highly effective. Modern public health initiatives need not just be effective, they also need to be *cost-effective*. Achieving impact with the least effort and financial expenditure, is increasingly important, and this goal has led to increasing use of an approach that involves planning change without the complex preparatory stages identified by Egan. Based on the work of implementation intentions (Gollwitzer and Schaal, 1998) (see Chapters 5 and 6 ☛), one version of this approach encourages individuals to briefly (typically for around five minutes or so) plan when, how, or under what circumstances they will engage in their behaviour of choice or make one behavioural change.

Some interventions have targeted relatively simple or short-term behavioural change. De Nooijer et al. (2006) found that writing plans to eat an extra serving of fruit per day for one week resulted in a higher intake of fruit than a no-treatment condition. Sheeran and Orbell (2000) found implementation plans resulted in higher attendance at a cervical screening clinic than a no-treatment condition. Even more impressively, Conner and Higgins (2010) found forming implementation plans resulted in a higher rate of quitting or later initiation of smoking than no intervention among adolescents, while Luszczynska et al. (2007) found that they significantly enhanced the effectiveness of a weight loss programme for obese women. Women who were on a standard commercial weight loss programme achieved a weight loss of 2.1 kilograms over a two-month period, while those given the implementation planning intervention achieved a weight loss of 4.2 kilograms over the same period. Gratton et al. (2007) found an intervention based on implementation plans to be equally effective as one designed to enhance motivation in relation to children's fruit and vegetable consumption. Summarising the data relevant to one key health behaviour, fat intake, a meta-analysis by Vilà, Carrero and Redondo (2017) reported an overall moderate effect size across twelve relevant studies, which was particularly evident among men and in interventions with no monitoring of behaviour during the intervention. Of particular interest are the findings of Adriaanse et al. (2011b) whose similar analysis found this approach to be better at increasing the intake of healthy foods than decreasing unhealthy intake.

# Mass persuasion through the media

One obvious way to address large population groups is through the mass media. The earliest media campaigns adopted a 'hypodermic' model of behavioural change, which assumed a relatively stable link between knowledge, attitudes and behaviour (something we now know to be somewhat optimistic: see Chapter 5 ☛). The approach assumed that if we could 'inject' appropriate information into the recipients, this would change their attitudes and in turn influence their behaviour. The reality is much more complex, and even simple attempts to persuade individuals to attempt change need to be much more sophisticated, as do the channels through which persuasion is attempted. Facebook, Instagram, Twitter, and Snapchat may now have more reach and influence than the so-called mainstream media for both professionally mandated (e.g. Wozney et al., 2019) or more populist information. It has been estimated, for example, that 31 million people follow antivaccine groups on Facebook and 17 million follow them via YouTube. An estimated 7–8 million people have become followers since the COVID-19 pandemic (Burki, 2020).

Appropriate planning and development of a programme is crucial. Crosby et al. (2019), for example, revealed the questions asked in the planning process of a series of advertisements targeted at young smokers. Despite this being published in a high impact health journal, while reading the list, note the absence of any clear link to psychological theory and practice:

- *Will this be unexpected?*
- *Does the advert address the problem in a novel manner?*
- *Is the message likely to surprise recipients?*
- *Does the intervention involve the innovative use of technology and/or media?*
- *Will this make young people stop and think?*
- *Does the intervention involve a new insight into the issue?*

- *Will the message trigger teens to re-evaluate their beliefs and attitudes in relation to smoking? Will it make them 'hyperconscious' of the risks every time the inhale tobaccos smoke?*
- *Does the advert include incontrovertible scientific data to support its message?*
- *Will this elicit an emotional reaction?*
- *Is the planned intervention likely to elicit a powerful emotional reaction?*
- *Will it be memorable?*
- *Is the idea so compelling that a young person will bring it to mind when they are offered a cigarette?*
- *Will the planned programme elicit feelings of health threat, disgust, or guilt in the moment of smoking?*
- *Will it make young smokers rethink whether the immediate pleasure of smoking is worth its long-term health costs?*
- *Is there immediacy to the message?*
- *Does this execution make the health consequence feel more tangible, more contemporary, and more urgent?*
- *Will young people reject the message on the grounds that bad things only happen to adults or long-term smokers?*
- *Could it change social norms?*
- *Could the ideas in the message be so relevant that they change how young people think, be parodied in other contexts or even become integrated into young people's idiom?*

## WHAT DO YOU THINK?

There is a flourishing anti-vax movement in the UK and many other countries. As noted in the main text, it has been estimated that 31 million people follow anti-vaccine groups on Facebook and 17 million follow them via YouTube. An estimated 7–8 million people have become followers since the COVID-19 pandemic (Burki, 2020). Anti-vax information is now spreading to platforms used by younger people, such as TikTok, where it is estimated that the hashtag #vaccinesaredangerous has had more than a million views. At a time of 'alternative facts', false news, and significant media disinformation, the mainstream political/medical messages may be lost within a wider environment of badly informed or inappropriate health messages. So concerned are politicians, that the UK labour party has asked for new censorship laws to ban anti-vax claims on social media. So, a key issue now is not just how to get messages to target populations, but how to manage disinformation and highly active disinformation sources.

At a time when science 'fact' has been eroded for many years (see, as another example, climate change deniers), the challenge to counter these views is significant. The issue can be considered one of personal freedom, but one has to question where does personal freedom and personal responsibility begin and end? As an example, the rates of MMR vaccinations in south Wales were so low due to an influential anti-vax movement that an outbreak of measles in 2013 affected over 800 children and resulted in at least one death, while in 2018, emergency MMR vaccinations were organised following a smaller outbreak to prevent it spreading. Herd immunity was lost, placing many thousands of children at risk.

At a time when anti-vax messages are increasingly accessible (and with the onset of the COVID-19 vaccinations arguably increasingly important), how should public health bodies and governments respond to these groups. Should they ban their messages, directly challenge them through advertising, make all vaccinations compulsory, stop unvaccinated children attending school, or adults entering the workplace? How accepting of diverging messages should we be? And how do we minimise the harm they may cause?

Despite its wide reach and relatively low cost, a critical question is whether media campaigns can result in any behavioural change. Isolated health campaigns frequently have little impact or even visibility and, as a consequence, some have argued that media campaigns are best used to raise awareness of health issues rather than to engender significant behavioural change (Huberty et al., 2012). Even long-term media campaigns may struggle to raise awareness or behavioural change. In Massachusetts, for example, only just over half the population noticed anti-smoking advertisements placed at least weekly over a period of three years. Those who did notice them reported increases in the perceived harm of smoking and stronger intentions not to smoke (Emery et al., 2007). Similarly, Hyland et al. (2006) found a 10 per cent increase in the likelihood that people would quit smoking for every '5000 units of exposure' to anti-smoking television advertising over a two-year period, while McVey and Stapleton (2000) calculated that an 18-month long British anti-smoking advertising campaign resulted in a modest 1.2 per cent reduction in smoking levels.

Others have noted that behavioural change is most likely when the target behaviour is a one-off or episodic behaviour, such as attending a vaccination or screening clinic (Wakefield et al., 2010) or when media campaigns form one element of a multi-modal intervention. A nice example of embedding advertising within a more complex intervention can be found in one anti-smoking programme targeted at young people. Zucker et al., (2000) reported that their US 'truth' (anti-tobacco marketing) campaign, which involved 'in-school education, enforcement, a school-based youth organisation, community-based organisations, and [. . . ] an aggressive, well-funded, counter-advertising programme' resulted in a 19 per cent reduction in smoking among middle-school students, and an 8 per cent reduction among high-school students. There are also a number of psychological strategies through which media campaigns can be enhanced including the following:

## Using cues to facilitate change

The elaboration likelihood model, which identified a specific role for central processing and peripheral cues (see Chapter 6 ☛) provides relatively sophisticated ways in which both motivated and relatively uninterested individuals can be engaged by media campaigns. The model is explicitly one of attitudinal change, so it must be judged from this perspective. The majority of studies (e.g. Flynn et al., 2011) have shown that information containing carefully chosen peripheral cues can facilitate attitudinal change in people who are relatively unmotivated to consider particular issues, and that combining central processing with peripheral cues has enhanced the effectiveness a range of interventions, at least in the short-term. By contrast, the central route may be particularly relevant and engaging to people with high levels of 'need for cognition'; a personality trait that involves a preference for information and willingness to engage in effortful cognitive activities. Such individuals have been shown to be more likely to engage, change their attitudes and maintain these changes following exposure to counter arguments than those who score lower on this trait (e.g., Nikoloudakis et al., 2018).

## The use of fear

There are good theoretical and empirical reasons to suggest that interventions based entirely on fear arousal are likely to be of little benefit (see Chapter 6 ☛). The limitations of this approach can be demonstrated in both the UK and Australian governments' classic fear-based appeals attempts to change sexual practices in response to the development of HIV/AIDS. Both countries used high-fear messages, including visual images of the chipping of a gravestone with the words AIDS (in the UK) and a celestial bowling alley in which a 'grim reaper' representing HIV bowled down families and children (in Australia). These were associated with portentous messages declaring the need to avoid HIV infection and to use safer sex practices. The Australian advert can be watched on YouTube (search for 'Grim Reaper [1987]'). Both campaigns increased HIV-related anxiety in audiences that saw them, but they neither increased knowledge about HIV/AIDS nor triggered any behavioural change. Subsequent fear-based messages in relation to safer sex practices also failed to promote appropriate behavioural change (Lau et al., 2016) and may even have increased feelings of shame and scepticism (Slavin et al., 2007). Summarising the wider literature Earl and Albarracin's (2007) meta-analysis of HIV-specific fear appeals indicated that receiving fear-inducing arguments increased perceptions of risk but decreased knowledge and condom use. By contrast, resolving fear through HIV counselling and testing both decreased perceptions of risk and increased knowledge and condom use.

If fear messages are used, relevant theory (e.g. Witte, 1992) (see Chapter 6 ☛) suggests they need to be accompanied with simple, easily accessible strategies of reducing the fear. Empirical evidence for this can be found in Tannenbaum et al.'s (2015) meta-analysis of health-related fear appeal-based interventions. Their data showed an overall positive impact on attitudes, intentions, and behaviours. However, these gains were more likely when the perceived risk of no change was high, the message encouraged the belief that that behaviour change could be achieved (e.g., targeted self-efficacy) and targeted one-off behaviours such as use of sun protection cream (e.g. Witte and Allen, 2000) and breast self-examination (Chen and Yang, 2018). Longer term or more repetitive behavioural change were more difficult to achieve. More subtly, Brengman et al. (2010) identified individual differences in response to fear-based messages designed to increase physical exercise in sedentary office workers. One group of recipients was responsive to both threat and efficacy appeals, one to threat alone, and one to efficacy alone. Piloting of interventions in specific audiences and multiple strands of influence are clearly required in any intervention, as suggested by the PRECEED: PROCEDE model: something that will become a recurring theme through this chapter.

## Teaching coping strategies

One of the barriers to attending screening for risk of disease is concern about its outcome: 'What will be found? Do I really want to know'? Fear may both prevent people engaging in screening programmes (Ackerson and Preston, 2009) and be an outcome of them, even when participants are found to carry no or low additional risk of disease (e.g. Korfage et al., 2014). In this context, the best approach to reducing anxiety may involve teaching coping or anxiety management skills (see Chapter 13 ☛). Phelps et al. (2013, for example, found that providing women undergoing assessment of their genetic risk for breast cancer with a leaflet providing simple distraction techniques was enough to significantly reduce anxiety during the risk assessment process.

In another context, a study by Marteau et al. (1996) considered the very specific impact of two booklets given to women referred for **colposcopy** following an abnormal **cervical smear**:

1. A medical information booklet provided details on the nature of cervical abnormalities, the procedure and its likely outcomes than the standard information booklet. However, it did not suggest any coping strategies that the women might use.
2. A coping booklet provided brief information about the procedure they were about to experience, information on the likely outcomes of the procedure, and instructions on relaxation and distraction techniques (see Chapter 13 ☛) they could use to help them to cope before and during the procedure.

Their results suggested a specific effect of each aspect of the information given. All patients who received the booklets knew more about issues around the colposcopy than a group of patients who received the standard level of information. However, the women who received the medical booklet did not experience any reductions in anxiety as a consequence. By contrast, those patients given the coping booklet were less anxious when they attended the hospital for their operation than those who received either the medical or no booklet.

## Information framing

A more nuanced approach to the development of health messages involves 'framing' the message (see Chapter 6 ☛). Health messages can be framed in either positive (stressing positive outcomes associated with action) or negative terms (emphasising negative outcomes associated with failure to act). While some have argued that negative frames are more memorable, others have suggested that positive messages enhance information processing. The latter may be particularly relevant when time is short, and individuals are not highly motivated to receive a message. Given these contradictory expectations, it may be no surprise that the related evidence can be conflicting, and complex to interpret. Both positive and negative framing of information have proven effective at times, but not in any consistent manner. Berenbaum and Latimer-Cheung (2014), for example, found that positive-framed communication about exercise was more influential than negative framed communication on outcomes as diverse as recall, attitudes, intentions, and actual behaviour. By contrast, Carling et al. (2010) found that both positive and negative framing resulted in higher uptake of anti-hypertensive medication than neutrally framed information. Van't Riet et al. (2010) found that computer-generated feedback on fitness plus gain-framed messages resulted in stronger intentions to be physically active than the same feedback with loss-framed messages but did not result in greater levels of exercise. Finally, Park et al. (2010) found message framing had no effect on

colposcopy

a procedure carried to closely examine the cervix, vagina and vulva for signs of disease; it may involve taking a deeper biopsy that would occur in a cervical smear

cervical smear

a procedure involving taking a smear of cellular material taken from the neck (cervix) of the uterus for detection of cancer attendance for screening for type 2 diabetes. Clearly, any interventions using message framing need to assess their impact on behaviour in pre-intervention pilot studies, to ensure the optimal approach is being used.

## Audience targeting

Early attempts to influence behaviour via the mass media frequently targeted whole populations, whether their targets or messages were relevant or not. Early media approaches promoting safer sex, as noted above, were based on fear messages, and the same messages were received by all, whether they were elderly, non-sexually active widows or young sexually active men enjoying multiple partners. The outcome of such an approach was instilling unnecessary fears among a group of people for whom HIV/AIDS had little immediate relevance, while not speaking the language of, or giving relevant advice to, the groups for whom it was most relevant. Now, media messages on sexual behaviour are more carefully targeted and use the language of their differing target audiences, making them much more effective.

Audience targeting can be based on a number of factors, including behaviour, age, gender and socio-economic status – each of which is likely to influence the impact of any message (Flynn et al., 2007). The change4life (https://smarttools.change4life.co.uk) campaign in the UK, for example targeted several thousand families with children aged 5–11 years, sending each family a questionnaire and sending back an individual action plan to enhance their children's health as well as providing a wealth of information online. Interventions may even be developed by the target audience. Bethune and Lewis (2009) aimed to increase Maori women's use of cervical screening services and used focus groups with 'priority women' and other key informants to identify the key messages likely to influence their behaviour. The intervention worked and resulted in an increase from 7 to 13 per cent in screening uptake over a one-year period. The relative cost-effectiveness of this intervention is clear. A further, simple, example of this social targeting process is afforded by the Terrence Higgins Trust leaflet in Photo 7.1, which would be considered outrageous by many, but fitted the profile of its target audience – young, sexually active, gay men – well.

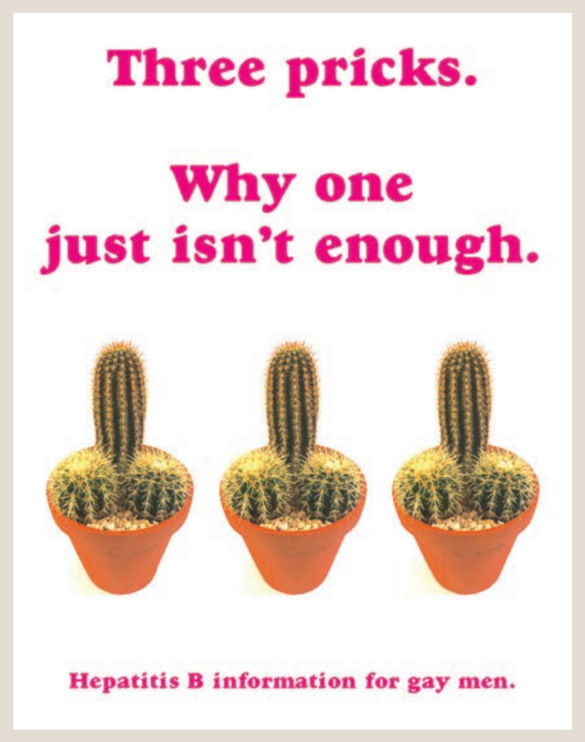


**Photo 7.1** An example of a health promotion leaflet targeted at gay men – with a sense of humour – encouraging them to have three vaccinations against hepatitis, produced by the Terrence Higgins Trust

*Source*: Terrence Higgins Trust.

Audiences may also be segmented along more psychological factors such as their motivation to consider change. While many studies have compared specific interventions targeted at individuals within different phases of the transtheoretical model (see for example the study of CHD screening by Steptoe et al. reported earlier in the chapter), others have attempted to address people with different levels of motivation within one integrated intervention. Sanaeinasab et al. (2018), for example, developed an educational programme designed to improve ergonomic posture in office computer workers. The five-session programme embedded within an educational programme included components likely to engage individuals who were actively willing to consider or make changes and those who were not. The former included group sessions focusing on the process of change, while the latter involved discussion of participants' attitude to change and those of others who might value or not value change. Compared to a no intervention control, the programme resulted in a significant shift among all participants towards the action stages of the model, as well as better posture while working and less back pain.

# Environmental interventions

Behavioural change does not occur in isolation from the environment. The health belief model (Becker et al., 1977) (see Chapter 5 ☛) provides some simple clues how environmental factors may be manipulated to enhance any likelihood of change. It suggests that an environment that encourages healthy behaviour should:

- provide cues to action or remove cues to unhealthy behaviour;
- enable healthy behaviour by minimising the costs and barriers associated with it;
- maximise the costs of engaging in health-damaging behaviour.

## Cues to action

Two key areas where cues have been used to either decrease unhealthy behaviour or increase health-promoting behaviour involve information provided at the time of purchase: health warnings on cigarettes and nutritional information on food. These approaches may be of some benefit, although the evidence suggests that they reinforce existing behaviour rather than prompt consideration of behavioural change.

Part of this lack of effect may be due to poor understanding of the issues raised and/or the low visibility of such cues. Cowburn and Stockley (2005), for example, in a review of over a hundred relevant papers, reported that many people in the general public, and particularly those on low incomes, did not understand, or were uninterested in, the nutritional information on food packaging. One South African study (Jacobs et al., 2010), for example, reported that the vast majority of the respondents to their survey only took notice of the expiry date of the food. Nutritional information was considered far less important, with participants favouring taste and price over nutritional content. In addition, many participants did not understand the information provided and were therefore unable to use it to inform health-related decisions. Similarly, Krukowski et al. (2006) found that less than half their sample of US college students looked at food labels or said they use the information of food labels even if available. It is possible that much of the information provided on food packaging is now simply too complex to be of value in triggering appropriate behaviours: simpler messages (low fat, high fibre, and so on) may be much more effective. Hersey et al.'s (2013) review of 38 relevant papers concluded that these simpler labels are more effective in increasing product information and likelihood of healthy purchases than more complex numerical information.

What *has* proven effective is the use of cues and provision of healthy foodstuffs at point of sale in retail outlets as varied as supermarkets and vending machines. A number of studies have shown consistent gains in the purchase of healthy foodstuffs if there are, (i) monetary rewards for doing so (or at least cheaper foods), (ii) they are easily purchased at any point of sale from supermarket to vending machine, and any nutritional and, (iii) price gains are clearly advertised (e.g., Hua et al., 2017). A combination of all three strategies appear more effective than the simple provision of nutritional information. By contrast, *reducing* consumption of high-calorie, sugar-sweetened beverages has been shown consistently achievable through traffic light labelling as high calorie at point of sale. Improved availability of more healthy drinking choices may also be of benefit (von Philipsborn et al., 2019).

Much simpler cues, reminding people to engage in health-promoting behaviours may also be of value. One simple example can be found in posters reminding people to use stairs instead of lifts or escalators. Webb and Eves (2007) found that posters encouraging people to use the stairs instead of a nearby escalator in a shopping centre resulted in a near doubling of stair use. Of particular note, was that the same research team found overweight individuals were more likely to respond to the signs than individuals of more average weight, suggesting this may be a simple but effective way of increasing fitness among this group particularly as those who do walk up the stairs are more likely to continue walking up subsequent stairs (e.g., Webb Eves and Smith, 2011). These individuals may also act as models, encouraging others to climb the stairs rather than use the escalator.

The history of anti-smoking adverts provides further example of attempts to prevent unhealthy behaviour. Borland (1997) evaluated the effect of introducing larger and clearer health warnings on standard cigarette packets. Increasing the size of the warning doubled the number of smokers to take notice of it. The numbers refraining from smoking as a consequence of the warning also doubled; from 7 to 14 per cent. A significant impact was also obtained by using graphic imagery rather than written text (Thrasher et al., 2007).

The trend across some countries to enforce standard packaging of cigarettes also appears to be of benefit. In December 2012, for example, Australia introduced drab olive-green packets with large graphic health warnings; packaging subsequently adopted by EU countries, including the UK, in 2017. Brose et al. (2014) found this packaging was less appealing and less likely to motivate the purchase of cigarettes than previous packaging. Interestingly, smokers using them were seen as less attractive, and the taste of cigarettes was considered less pleasant. Moodie and Mackintosh (2013) found smokers smoked less and were more likely to consider quitting than previously.

Environmental cues can also act as reminders to behave in unhealthy ways. Frequent exposure to relevant advertising, for example, has been shown to increase perceptions of the prevalence of smoking (Burton et al., 2010) as well as increase cigarette (Sargent et al., 2000) and alcohol use (Smith and Foxcroft, 2009) among young people. Accordingly, those involved in public health frequently strive to limit and legislate against such things as tobacco and alcohol advertising. The UK government, for example, banned television advertising of tobacco in 1965 and totally banned its advertising from 2003. The effectiveness of this approach appears to differ across countries and contexts. Quentin et al. (2007), for example, reported that total bans on advertising of tobacco products were associated with mixed reductions in consumption. Of the 18 studies they reviewed from various countries, only ten reported a significant reduction in smoking following the ban; two studies suggested a partial ban on advertising had little or no effect.

Of course, advertising is not the only media influence on attitudes to health-related behaviour, some of which may be less supportive of appropriate behavioural change. The portrayal of alcohol consumption in films, music videos and soap operas for example, has been shown to influence the onset and progression of consumption among young people (Koorderman et al., 2012). The net impact of these images and messages is that any health advertising is competing against a background of complex and influential processes. Any gains should therefore be applauded.

## Making healthy behaviour an easier choice

The environment in which we live can either facilitate or inhibit our level of engagement in health-related behaviour. Poor street lighting, busy roads and high levels of pollution may inhibit some inner-city dwellers from taking exercise such as jogging or cycling; shops that sell healthy foods, situated a long way from housing estates may result in more use of local shops that sell less healthy foodstuffs, and so on. Making the environment safe and supportive of healthy activity presents a challenge to town planners and governments. Such an environment should promote safety, provide opportunities for social integration and give the population control over key aspects of their lives.

A number of projects, under the rubric of the 'Healthy Cities movement' (e.g. World Health Organization, 1988), have attempted to design city environments in ways that promote the mental and physical health of their inhabitants. The movement initially involved cities in industrialised countries but is now expanding to include cities in industrialising countries such as Bangladesh, Tanzania, Nicaragua and Pakistan. To be a member of the movement, cities have to develop a city health profile and involve citizen and community groups. Priorities for action include attempts to reduce health inequalities as a result of socio-economic factors (see Chapter 2 ☛), traffic control, tobacco control, and care of the elderly and those with mental health problems.

Unfortunately, while very laudable, this rather broad set of strategies has proved difficult to translate into measurable and concrete action. Nevertheless, where appropriate measures have been used and appropriate environmental changes made, this does seem to influence health behaviour. Jago et al. (2005), for example, found that levels of low intensity exercise were greater among male adolescents when there was good street lighting, safe areas for jogging or walking, well-maintained pavements, and the presence of trees. More specific studies have shown that environmental manipulations aimed at minimising the costs of engaging in exercise may result in significant change. One study, in the context of a closed community naval base (Linegar et al., 1991), took advantage of this to manipulate both its physical and organisational environment. They established cycle paths, provided exercise equipment, and organised exercise clubs and competitions within the base. In addition, they gave workers 'release time' from other duties while they participated in exercise. Not surprisingly, perhaps, this combination of interventions resulted in significant increases in exercise, even among people who had not previously exercised.

A more realistic programme, intended to increase levels of exercise among women in a suburb of Sydney, was reported by Wen et al. (2002). It targeted women aged between 20 and 50 years through a marketing campaign and increased opportunities for participation in exercise. The marketing included establishing community walking events and initiating walking groups and community physical activity classes. Local council members were invited on to the project group to raise the profile of the project with council members and to ensure that the project fitted within the council's social and environmental plans. Pre- and post-project telephone surveys indicated a 6.4 per cent reduction in the proportion of sedentary women in the local population, as well as an increased commitment to promoting physical activity by the local council. In a review of 21 similar studies, Fraser and Lock (2010) found that factors associated with higher cycling prevalence included the presence of dedicated cycle routes or paths, separation of cycling from other traffic, proximity of a cycle path or green space; and for children, projects promoting 'safe routes to school'. Caution should be taken before assuming such approaches will inevitably result in behavioural change, however, as only four of seven cycling initiatives involving establishing cycle lanes resulted in increased levels of cycling.

From an even broader perspective, the Australian 'Active Launceston' programme (http://www.activelaunceston.com.au) delivered over 225 free physical activity programmes including both indoor and outdoor activities combined with an advertising programme, reaching over 12,750 participants over a 10-year period. Their goal was to increase physical activity in those with 'limited or poor knowledge of opportunities, low self-esteem, prohibitive costs, and social disconnection'. Disappointingly, despite all these efforts, they found no overall increase in the proportion of the local population engaging in physical exercise at the end of a three-and seven-year evaluation period (Byrne et al., 2019): sustained increases in exercise among low or no exercisers appeared to be unrelated to opportunities to do so.

**Photo 7.2** Making ways of achieving exercise easy and cheap to access may both increase health and save the environment

*Source*: Veniamin Kraskov/Shutterstock.

**IN THE SPOTLIGHT**

### The binge drinking epidemic

Despite some reductions in the consumption of alcohol throughout the population, many countries have significant levels of binge drinking, particularly among young people. This phenomenon has been reported, for example, in the UK, New Zealand, Australia, an area known as the vodka belt (Russia and other countries where vodka is the primary drink) but is less prevalent in South America and southern Europe. The causes of this behaviour are not fully understood, but the availability of cheap alcohol in supermarkets, clubs and pubs – and the culture of drinking while standing – is widely recognised as contributing to the phenomenon. The drinking culture contributes to significant personal harm, as well as having a substantial economic and social impact on the affected communities. Some cities have increased policing in response to the social problems. Some have made bars contribute to the cost of this policing. But one French town took their approach a stage further. They bought the bars! The city of Renne, in Brittany, has bought two bars in the centre of town and converted one into a DVD shop, and one into a restaurant in an attempt to reduce alcohol consumption in its centre. Time will tell whether this impacts on alcohol consumption . . . but you have to admit, it's a pretty bold approach to health promotion!

## Making unhealthy behaviour more difficult

Making unhealthy behaviour difficult in some way (often through pricing) can act as a barrier to unhealthy behaviour and a facilitator of healthy behaviour. Economic measures related to public health have been largely confined to taxation on tobacco and alcohol (although this is changing as, for example, the UK has brought in a 'sugar tax' on soft drinks which has reduced the amount of sugar in soft drinks in order to avoid significant price rises and is considering a 'fat tax'. Taxation does work, particularly where any increase in price is substantial. Roodman (2020), for example, provided a 'rough rule of thumb' that for every 1 per cent increase in alcohol price the amount drunk across the general population will fall by 0.5 per cent. He estimated a 10 per cent price increase would cut the alcohol-related death rate, largely from cirrhosis, over time by between 9 and 25 per cent. The latter impact may be because heavy drinkers are those most likely to be affected by price.

A differing approach to putting barriers to unhealthy behaviours has involved restricting the number of outlets for drugs such as alcohol. This increases transaction 'costs' as people have to travel further and make more effort to purchase their alcohol, and in reduced cues to consumption from advertising in shop windows and other signs. Connor et al. (2010) found this approach to achieve modest gains, with more geographically widespread off-sales outlets across New Zealand being associated with less binge drinking and alcohol-related harm; there was no association between outlet density and frequency of 'sensible' drinking. By contrast, increasing availability, as occurred in Sweden after stopping its restriction of Saturday opening of alcohol retail shops, may result in increased consumption (Norström and Skog, 2005).

A more direct form of control over smoking has been the introduction of smoke-free public areas. This overall ban has frequently been preceded by a ban in work and social areas. Even the latter, limited, approach proved successful in terms of its health impact. Heloma and Jaakalo (2003), for example, found that secondary smoke inhalation levels fell among non-smokers, while smoking prevalence rates at work fell from 30 per cent to 25 per cent following a national smoke-free workplace law. Following a ban on smoking in Norwegian bars and restaurants, Braverman et al. (2007) reported significant reductions in the prevalence of daily smoking, daily smoking at work by bar workers, number of cigarettes smoked by continuing smokers, and the number of cigarettes smoked at work by continuing smokers.

Even more encouraging are data suggesting that such bans can positively impact on health, and that total bans on smoking augment any gains made by more limited constraints. Johnson and Beal (2013), for example, compared rates of myocardial infarction (MI: see Chapter 8 ☛) during a partial ban and then complete ban on smoking in North Dakota, USA, and found a 30 per cent reduction in the incidence of MI and 24 per cent reduction in hospital admissions with an MI. Equally, it not more importantly Been et al. (2014), reviewed eleven studies of the effects of second-hand smoke exposure by children, and found significant reductions in premature births, low birth weight children and asthma directly attributable to smoke free legislation.

# Public health programmes

So far, we have looked at some broad approaches to behavioural change in large populations, and some of the underlying principles that underpin them. The next sections of this chapter examine how these, and some other, approaches have been used in public health programmes targeted at whole populations and more specific target groups within them.

## Reducing risk for CHD

Some of the first public health programmes aimed to reduce the prevalence of key risk factors for CHD (see Chapter 8 ☛) across the entire adult populations of large conurbations. The first of these, known as the Stanford Three Towns project (Farquhar et al., 1977), provided three towns in California with differing levels of intervention:

- no intervention;
- a year-long media campaign targeting CHD-related behaviours;
- a media campaign augmented with individual interventions targeted at high risk individuals.

The media programme began by alerting people to the need to change their behaviour (itself a relatively novel message in the early 1970s). This was followed by a series of educational programmes providing information and modelling behaviour change; for example, by broadcasting films of people attending smoking cessation groups or teaching cooking skills. These were aimed at teaching skills and increasing recipients' confidence in their ability to change. The third town benefited from an additional intervention in which people identified at high risk for CHD received one-to-one behavioural counselling and were asked to disseminate their knowledge through their social networks.

By the end of the one-year programme, a measure of overall CHD-risk status showed average risk actually rose in the control town, while they fell significantly among the general population who received the media campaign alone and fell to an even greater extent among those who lived in the town that received the combined intervention (Farquhar et al., 1990). Unfortunately, this success has not been replicated in almost all subsequent large-scale interventions, including those using strategies including provision of low fat and healthy eating foodstuffs and public exercise facilities, labelling of food as high/low fat, screening for CHD risk factors, free classes teaching healthy eating, access to smoking cessation groups and smoke free areas at work.

These data are clearly disappointing. Indeed, they provide little encouragement to suggest that the approaches they used should be continued. However, before they are dismissed, it is important to contextualise their findings. First, apart from the original Stanford study, they occurred at a time when there were significant changes in health behaviour and disease throughout the countries in which the studies were conducted. Rates of CHD fell by 20 per cent over the time they were running (Lefkowitz and Willerson, 2001), and there was a general increase in health-promoting behaviour and a concomitant fall in health-damaging behaviour such as smoking.

Most of the information about heart disease is now probably provided by the mass media, including discussion of healthy diets, issues such as men's health, and so on, are mainstream and difficult to avoid. It is therefore increasingly difficult for any public health programme to add further to this information. Interestingly, however, when community interventions are run in countries with a relatively short or limited experience of public health programmes, the same positive results are found as in the initial Stanford Study. Lv et al. (2014), for example, found a two-year community-based intervention in China which involved interventions including those identified in Table 7.1, reduced levels of smoking, and increased levels of exercise compared with those in a control area. Significant gains in healthy eating were made in both

**Table 7.1** Examples of multilevel interventions

| Level | Examples of interventions |
|---|---|
| Individual | Establishing health-related messages through a range of media and other channels;<br>Making utensils necessary for healthy lifestyle available: including salt spoons and oil pots;<br>Providing free health screening and risk assessments for cardiovascular disease;<br>Providing fitness testing; |
| Social environment | Encouraging health professionals to screen for risk and to provide (behavioural) prescriptions for health;<br>Starting social exercise groups such as walking clubs;<br>Encouraging dialogue between parents and children promoting healthy lifestyle; |
| Physical environment | Implementing smoke-free worksite environments;<br>Instituting smoking bans in public areas;<br>Using prompts to increase use of stairs and avoiding escalators/lifts;<br>Building walking trails with distance markers in easy walking contexts<br>Establishing a public bicycle service system;<br>Providing healthy eating choices in restaurants and workplace cafeteria;<br>Making food content and calorie information available to consumers in restaurants and other public eating areas; |
| Policy environment | Smoke control regulation in public places<br>Engagement with the World Health Organisation healthy city movement |

Source: Lv et al. (2014).

## RESEARCH FOCUS

### Making healthy 'convenience' food accessible increases its uptake

Corben, K., Blake, M.R., Palermo, C. et al. (2017). The effect of a change to healthy vending in a major Australian health service on sales of healthy and unhealthy food and beverages. *Appetite*, 114: 73–81.

Vending machines provide easy access to food and drink and provide a potential point of intervention to facilitate increased use of healthy food and beverages. However, the risk of using them from a corporate perspective is that shifting their contents from popular less-healthy provisions may reduce sales, and profits. This study aimed to find out whether this was, indeed, the case. It examined purchases from 37 vending machines in three major Australian hospital sites before and after implementation of a healthy food and beverages policy.

### Method

The study used a mixed-methods approach to measure the impact of the introduction of products available through 37 vending machines in three major hospitals identified through a traffic light system as more or less healthy. Based on their nutritional content (including levels of fats, sodium, fibre and calorific content), food and drink items available in the vending machines were labelled as red (a maximum of 20 per cent of available purchases), amber (around 30 per cent) and green (at least 50 per cent of available products).

A time-series analysis was used to measure sales of the items identified as being more or less unhealthy. Prior to the study these were unmarked; after, identified with the traffic light system. Sales were monitored for 30 months prior to establishing the traffic light procedure, when the normally available items were available, and for 12 months following its institution. In addition, interviews were conducted with a number of 'stake holders': a 'health promotion manager', senior hospital executive, the procurement manager and the main dietitian involved in the policy implementation. They were each asked a number of questions addressing:

- the impact of the implementation on sales;
- consumer reactions to the changes;
- the most important issues in the process of implementation.

*(continued)*

**Table 1:** Monthly consumption of food and drink items before and after policy implementation

| | Number and per cent of items at baseline | Number or percent change in sales at one-year follow-up (and 95% confidence intervals) |
|---|---|---|
| Food items | | |
| 'Green' | 0 items (0.0%) | 155.8 items (136.3, 175.4) |
| 'Amber' | 931 items (19.9%) | 30.5% decrease (9.2, 70.3) |
| 'Red' | 4709 items (80.2%) | 55.0% decrease (73.3, 37.5) |
| Drink items | | |
| 'Green' | 645 items (17.1%) | 21.9% increase (4.4, 39.4) |
| 'Amber' | 786 items (20.8%) | 21.9% decrease (36.8, 7.0) |
| 'Red' | 2343 items (62.1%) | 56.1% decrease (67.1, 45.1) |
| Volume of sugary drinks (litres) | 1263.0L | 61.2% decrease (73.2, 49.2) |

## Findings

### *Quantitative analysis*

Data presented show consumption levels in the month before the policy implementation and the equivalent period one year later. The findings were impressive, with all changes in the desired directions, with significant gains on healthy 'green' food items and reductions in both food and drink items labelled as amber or red (see Table 1). A similar pattern was found for beverages, with a drop of 846.9 fewer litres of sugary sold over the month, resulting in a reduction of nearly 70 per cent reduction in kilograms of sugar consumed over this time.

### *Qualitative analysis*

The qualitative data was subject to thematic analysis, in which common themes across the respondents were identified and labelled, as well as sub-themes contributing to the wider themes. Key contributors to the successful implementation were that the intervention was justified by state government guidelines on healthy eating and facilitated by strong executive support at the highest level within the hospital management. The intervention was seen as 'the right thing to do', and the potential loss of earnings (to the hospital) from sales was seen as both small in terms of overall hospital revenue and justifiable on health and political grounds. More problematic were problems in resourcing the 'green' options, although due to wider changes in the food industry, resourcing 'amber' options was less difficult. The project team worked with the vendor suppliers to identify green and amber products and to help them source them.

## Discussion

The intervention proved successful, with minimal publicity and effort. Despite problems in sourcing sufficient 'green' items for sale and, on occasion, a lower percentage of amber and green items available through the machines than was planned, their provision resulted in significant improvements in the consumption of health food and beverages. The project was considered successful, and future plans involved moving 'healthy' vending machines to areas of the hospital with higher footfall. It was disappointing not to have explored the views of those using the machines to identify how and why these changes were found, and the acceptability of the offerings. It is possible, for example, that if confronted with an unpalatable choice of foodstuffs, people simply went to other vending machines to obtain their preferred choice. So, it would be interesting to consider the sales in other vending machines that users could have accessed over this time period. Nevertheless, these data are encouraging, suggesting the even small 'nudges' can prove effective in changing behaviour.

intervention and control areas. It appears this type of intervention can be effective, but only in certain contexts and at certain times in the cycle of population knowledge of CHD.

## Reducing risk of sexual transmitted disease

In contrast to interventions targeted at CHD, those targeted at sexual behaviours appear to have been successful across both industrialised (Simoni et al., 2011) and developing (Medley et al., 2009) countries. Given the devastating impact of HIV/AIDS in Africa, interventions here are of paramount importance, and in many ways similar to those used to combat CHD. Galavotti et al. (2001), for example, described an approach known as Modeling and Reinforcement to Combat HIV (MARCH), developed by the US Centers for Disease Control for use in a number of African countries, and modified from a pre-existing US media approach. The intervention model had two main components: (i) use of the media and (ii) local influences of change. It used the media to provide role models in 'entertainment that educates' by providing information on how to change and modelling appropriate changes in sexual behaviour. Serial dramas on television were also used to educate, because they were thought to involve the viewer emotionally with the action on the screen. This was thought to increase its personal relevance and encouraged viewing. Interpersonal support involved the following: creation of small media materials such as flyers depicting role models progressing through stages of behaviour change for key risk behaviour, the mobilisation of members of the affected community to distribute media materials and reinforce prevention messages, and the increased availability of condoms and bleacher kits for injecting drug users.

In one study of effectiveness of media approaches using these strategies (Vaughan et al., 2000), Radio Tanzania aired a radio soap opera called *Twende Na Wakati* ('Let's go with the times'). This soap played twice weekly for two years with the intention of promoting reproductive health and family planning and preventing HIV infection. In comparison with an area of Tanzania that did not receive national radio at the time of the study, people who lived in areas where the radio programme was received reported greater commitment to family planning and higher uptake of safer sex practices. In addition, attendance at family planning clinics increased more in the intervention than control area.

Positive outcomes have also been achieved using an approach called peer education (Simoni et al., 2011). In this, opinion leaders and other key players within specific communities are involved in projects and form a key part of the programme. The approach draws upon social learning and diffusion theory (Figures 8.1), as these individuals provide particularly strong role models of change within a specific community. Using people known and respected within a particular community also makes their message salient and shows that appropriate change can be achieved.

In an early trial of this approach involving interventions in eight US cities (Kelly et al., 1997) gay men, identified as key influencers within their local community, were taught elements of safer sex and given educational materials they could distribute. They then talked to men they met in gay bars with a view to educating them about the need to practice safer sex and how to do so. As a consequence of the intervention, levels of unprotected anal intercourse fell from 32 to 20 per cent among men frequenting the bars in which the intervention was conducted; this, in contrast to a two per cent rise among those in the control cities. Since then, this approach has been adopted by many programmes, and the findings have been replicated across the world (e.g., Lau, Tsui and Lau, 2013). Using a more formal approach, in which heterosexual women provided peer education in small group settings, Davey-Rothwell et al. (2011) found similar reductions in unsafe sex practices among participants both in terms of lower numbers of sexual partners and higher use of condoms.

This approach may also work in more unusual contexts including prisons, where peer education has been successfully shown to increase uptake of HIV testing (Ross et al., 2006). In another challenging environment, Asamoah-Adu et al. (1994) engaged prostitutes in Ghana to provide peer education and distribute condoms to their fellow prostitutes, resulting in a significant reduction in unsafe sex. Overall, the women who took part in the intervention were more likely to use a condom than they were prior to the intervention. In addition, three years after the end of the formal programme, women who maintained contact with the project staff were more likely to continue using condoms than those who did not maintain contact.

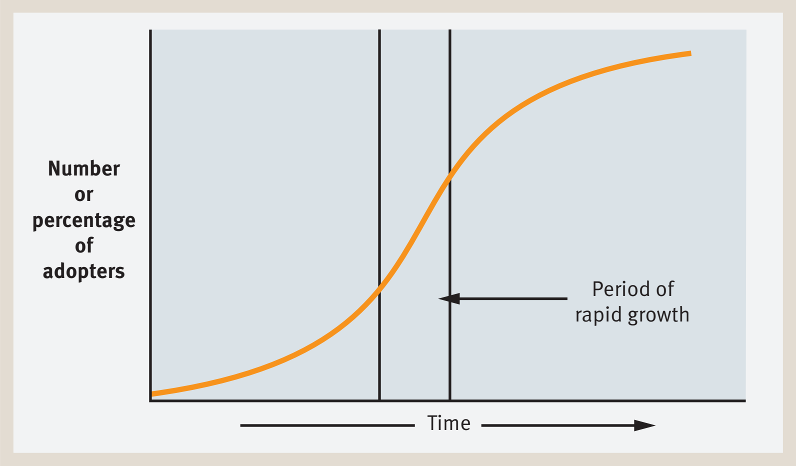


**Figure 7.1** The S curve of diffusion, showing the rate of adoption of innovations over time.

## Worksite public health

One response to the problems encountered by large-scale population interventions has been to target smaller, more easily accessible and 'controllable' target groups. As such, the past few decades have seen the development of many impressive public health programmes in the workplace. The majority of these have been conducted in the USA, perhaps because enhancing the health of the workforce reduces the cost of workers' health insurance often paid by the employer, and sickness absence, and therefore benefits the company as well as the individuals in it. As an example of this, Jensen (2011) concluded that diet-related worksite interventions improved labour efficiency by 1–2 per cent as a result of reduced absenteeism.

Worksite programmes have targeted a range of health-related behaviours, including diet, exercise, smoking and stress (generally focusing on risk factors for CHD and cancer). Because the worksite offers a wide possibility of interventions, a variety of formats have been utilised, including some innovative approaches:

- screening for risk factors for disease;
- providing health education;
- provision of healthy options, such as healthy food in eating areas;
- providing economic incentives for risk behaviour change;
- manipulating social support to facilitate individual risk behaviour change;
- provision of no-smoking areas (and more recently smoking rooms) in the work environment.

More succinctly, these may be thought of as interventions which reward healthy lifestyles or punish unhealthy ones. Mujtaba and Cavico (2013) outlined a range of interventions, placing them into the categories of 'carrot' or 'stick'.

Carrots included:

- providing gyms at work and/or free gym membership
- providing low-fat meals in the cafeteria
- employers making contributions to health insurance if people have or adopt a healthy lifestyle, have markers of good health (appropriate weight, low cholesterol, and so on), or engage with some sort of behavioural programme in order to improve health.

Sticks included:

- higher healthcare insurance premiums for unhealthy employees
- increasing 'deductibles' for employees with unhealthy lifestyles who fail to meet healthcare standards
- not hiring job applicants who are smokers, overweight or otherwise unhealthy.

Perhaps the simplest intervention involves providing information on the nutritional and calorific content of food provided in dining areas. However, reflecting the general weakness of low-key educational interventions, there is no evidence that this simple approach is likely to be successful (Engbers et al., 2006). Accordingly, a number of studies have developed more complex interventions, with many still focusing on education, albeit at a relatively sophisticated level. In one such intervention, Geaney et al. (2016) compared; (i) a nutritional educational intervention, (ii) an environmental manipulation involving changing menus to provide more healthy food, discounts for healthy foods such as fruit, 'strategic placing' of healthy alternatives in the serving areas and reducing portion sizes, and (iii) a combination of both approaches. The only significant gains, in comparison to a control no intervention condition, were found for the combined intervention. In this, significant gains were found on measures of knowledge, intake of saturated fat and salt, as well as modest reductions in BMI.

An even more direct approach to changing behaviour that is achievable within the controlled environment of a worksite involves the provision of rewards for successful changes in behaviour. In a review of this type of approach among smokers, Cahill, Hartmann-Boyce and Perera (2015) examined outcomes of studies providing a range of incentives for entering smoking cessation programmes and quitting. These included lottery tickets or prize draws, vouchers of goods and groceries and cash payments. The latter involved either direct payments for success or pre-payment of deposits prior to attempts at quitting and then payments back (plus or minus additional payments) contingent on successful quitting. This financial investment is considered to increase the psychological investment and motivation to change. Of the twenty-one studies they included in their analysis, only three achieved significant long-term gains; that is, benefits beyond the time participants received a reward for their behaviour. So, while participants may make behavioural changes while receiving rewards, the sustainability of these changes appears less consistent.

As an example of one successful trial, Halpern et al. (2015) compared the effectiveness of both individual and group-based smoking cessation interventions (versus no treatment), combined with either financial 'rewards' of up to $800 for sustained abstinence of six months or a deposit of $150 which was paid back over time and topped up to a total of $950. Interestingly, and contrary to the notion that personal investment should increase success rates, while all the incentive participants achieved higher levels of sustained abstinence than the control group, the only condition to achieve significant gains at 12-month follow-up was the rewards group, with a quit rate of 8.1 per cent. The deposit group only achieved a quit rate of 4.7 per cent. However, this study may be unusual in its impact.

A number of programmes have targeted people with specific health issues, including those who may potentially benefit from weight reduction. Such programmes have proven reasonably successful. Sorensen et al. (2010), for example, achieved some success when they provided a bespoke four-month long education plus telephone counselling programme designed to reduce tobacco use and enhance weight management among blue-collar workers identified as at risk for CHD in 17 US sea ports. Before running the programme, they ran a number of focus groups to identify particular issues relevant to their work environment which were then incorporated into recruitment materials, intervention messages and, where possible, in the counselling. Of 542 workers invited to participate, half agreed to participate and received at least the first telephone call. By ten-month follow-up, the quit rate was significantly higher among those in the counselling programme than those who did not participate (39 versus 9 per cent). However, they did not make concomitant gains in the weight management programme.

In a similar targeted programme, Olson et al. (2009) incorporated team weight loss competitions, computer-based behavioural change programmes, and telephone coaching using motivational interviewing. Over a period of six months, those involved lost an average of just under four kilograms. There was no control condition but given the typical trajectory of weight gain or at best maintenance among overweight individuals, this is at least suggests the possibility of benefit from such an intervention.

## WHAT DO YOU THINK?

Worksite health promotion programmes clearly aim to support appropriate health behaviours. But the very nature of some working environments may provide a more complex challenge to our health. Shift work, night shifts, stressful and traumatic incidents as a routine part of work, and the increasing shift towards 'precarious employment', with its inherent financial and time insecurities may all prove deleterious to health. So, we have two competing interests: business, which says such practices are inevitable and necessary, and the health imperative of minimising any negative health impact of work. These type of work structures impact most on workers in the lower socio-economic groups, who may have little choice of where and how they work. So, should employers have a responsibility to consider the health of their workforce when establishing jobs? Or is this a case of 'employee beware': the employees know the risks and choose to take on the jobs. It's their choice, and their health is not their employer's responsibility?

**Photo 7.3** Attractive healthy food served in the workplace can increase healthy eating rates

*Source*: CandyBox Images/Shutterstock.

## School-based interventions

School brings to mind traditional lessons: passively listening to the teacher providing information relevant to the topic under consideration; and a number of public health initiatives have used this type of model. James et al. (2007) reported short- but not long-term, gains following educational lessons such as these, targeted at health nutrition and weight control. School also provides a context in which health professionals can access students and act as agents of change. Pbert et al. (2006), for example, found that a smoking cessation intervention involving school nurses working with school students resulted in greater (self-report) abstinence rates than no intervention. School also brings connotations of discipline and control; but whether attempts at control impact on health behaviours is questionable. Evans-Whipp et al. (2010), for example, found that school policies that incorporated a comprehensive smoking ban, harsh and remedial penalties for those caught smoking, as well as more positive strategies had no impact on smoking levels in schools in the USA and Australia.

At a higher, systemic level, simple one-target interventions may be effective, particularly if they target pupils early in school life. In the Netherlands, for example, the *Schoolgruiten* project (Moore et al., 2010) gave 9–10-year-old pupils a free piece of fruit or ready-to-eat vegetables (tomatoes or baby carrots) twice a week in their mid-morning break (thereby not competing with the unhealthy foods that often preferred by children and available at mealtimes). The aim of this regular exposure was to both increase consumption and encourage a taste preference for fruit. A year after the inception of the project, children in the intervention group, but not their parents, reported they had a higher vegetable intake. By two-year follow-up (Tak et al., 2009), both children and parents reported higher levels of fruit intake among children in the intervention condition, although there were no differences in vegetable intake. Finally, the children in the intervention condition were more knowledgeable than those in the control condition.

A more complex systemic approach advocated by the World Health Organization (1996) has produced more mixed results. The WHO health-promoting schools initiative states that schools should prioritise the health of their pupils and develop an integrated approach to enhancing health, preventing uptake of unhealthy behaviour and educating pupils about health-promoting activities. This stops health education from simply being a taught part of the curriculum to something that is central to the aims of the school, and around which school activities and infrastructure are based. The framework which schools involved in this sort of programme typically adopt includes:

- ‘healthy policies’, such as a ‘no helmet, no bike at school’ policy for cycle safety or an Australian ‘no hat,

no play' policy (to avoid sunburn), as well as more traditional policies such as no smoking on school premises and no tolerance of bullying;
- establishing a safe, healthy physical and social environment;
- teaching health-related skills;
- providing adequate health services within the school;
- providing healthy food;
- school-site health-promotion programmes for staff;
- availability of school counselling or psychology programmes;
- a school physical education programme.

This approach has met with limited success, partly perhaps as a result of its complexity and limited uptake and implementation in schools where it has been advocated. In Hong Kong, Lee et al. (2006) found that schools which had most successfully implemented the various elements of the healthy schools evidenced the greatest improvements in diet and antisocial behaviour. Of particular note was that the scheme was more influential in primary rather than secondary schools.

Less optimistically, Schofield et al. (2003) established an intervention involving formal education addressing the health risks associated with smoking. Information leaflets and bi-weekly school newsletters for parents, letters to tobacco retailers, a smoke-free school policy development, encouragement of non-smoking parents, peers and teachers as role models, peer influence programmes and incentive programmes were all utilised. But when compared to schools that had not implemented these elements, no differences in smoking rates were found over a period of two years.

A Cochrane review led by Langford et al. (2014) came to equally modest conclusions. Their analysis of 67 trials involving the WHO framework, many of which were of low scientific quality, found some evidence of self-report improvements on fruit and vegetable consumption and exercise, but no gains on a key objective measure reflecting these factors, BMI, which forms a more objective and reliable measure of outcome. They also found reductions in self-report cigarette use, but no impact on fat intake, alcohol and drug use, mental health or bullying. It seems it is difficult to influence young people's behaviour against a slew of other less benign influences.

One final approach to health education in schools involves peer education. As in the social interventions to reduce the spread of HIV described earlier in the chapter, this typically involves training influential pupils in a school about a particular health issue such as smoking, alcohol consumption or HIV education and encouraging them to educate their peers about the issues, hopefully in a way that encourages healthy behaviour. The methods used vary considerably. They may involve teaching whole classes, informal tutoring in unstructured settings, or one-to-one discussion and counselling. In one study of this approach, Lotrean et al. (2010) examined the impact of combining peer-led discussions with teaching cigarette refusal skills in their smoking prevention programme targeted at 13–14-year-old Romanian school pupils. Compared to a control group who did not receive the intervention, the percentage of pupils to take up smoking was halved in the nine months following the intervention (4.5 versus 9.5 per cent).

A more informal approach to peer education in the context of smoking was reported by Campbell et al. (2008). In their study, pupils aged 12–13 years were asked to identify influential people within their social group. From this list, the intervention team identified a group of people who were particularly influential among the target population: some of whom may not have been the choice of their form teachers! Volunteers from this group were then taken to a hotel for two days, where they were given training in their peer education role. The training gave them information about short-term risks to young people of smoking, and the health, environmental, and economic benefits of remaining smoke-free. It also used role-play and small group work to enhance their communication skills, including verbal and non-verbal communication skills and conflict resolution. It aimed to enhance students' personal development, including their confidence and self-esteem, empathy and sensitivity to others, and assertiveness. Following their training days, the peer educators were asked to talk to their friends and anyone else they felt appropriate about smoking, sharing information and advice over a period of 10 weeks. This model of uncontrolled dissemination contrasts strongly with some of the more formal methods adopted by other programmes. Campbell et al. found that students in the control condition were significantly more likely to become a smoker at one- and two-year follow-up, than those who received the intervention and a subgroup of pupils they considered particularly at risk of taking up smoking.

Overall, among young people who have never smoked, peer lead approaches combined with training in social competencies to enhance ‘saying no’ do appear to be effective. In their meta-analysis of relevant trials, Thomas, McLellan and Perera (2015) found a 12 per cent lower uptake of smoking for up to a year following the intervention than among those not receiving an intervention. However, no benefit was found among those young people who were already smoking. Although less studies have been conducted focusing on alcohol, similar gains may be made in terms of low alcohol use among those who receive peer education (Georgie et al., 2016). This approach has proven highly successful in changing attitudes, confidence in sexual negotiation and normative beliefs; perhaps unsurprisingly, though, evidence of behavioural change is more equivocal (Mahat and Scoloveno, 2018).

## Using technology

The internet and mobile phone provide a simple technology for communicating with vast numbers of individuals and have been eagerly appropriated by many of those involved in public health. One obvious approach to using technology is to link interventions to widely used social media platforms such as Facebook, YouTube and so on. However, this does not guarantee success. Todorovic et al. (2019), for example, invited medical students to join a closed discussion group on Facebook which included motivation for physical activity through motivational pictures, texts, and discussions. Participants were grouped according to their exercise status at the beginning of the study. The intervention proved successful, but unfortunately only among those already engaging in relatively high levels of exercise: the ideal target group made no changes to their behaviour. In an evaluation of a more formal intervention, Byker, Myers and Graff (2019) found no evidence that receiving regular ‘advertisements’ via Facebook supporting the use of long-acting reversible contraception increased its use.

As with all interventions, to repeat the lessons cited earlier in the chapter, appropriate intervention development should ideally involve potential recipients of the intervention. In one such study, Hefler et al. (2019) indigenous Australians, acting as ‘community researchers’ regularly posted tobacco related posts of their choice on Facebook for a period of six months. These were tracked to identify the number of ‘shares’ by recipients. Posts that were relevant to the ethnic community, were child-focused, and perceived as practical, relevant and credible were most likely to be shared. Those that included challenging images and were either ambiguous and/or sarcastic were much less likely to be shared. Decisions about what to share and who to share with were based on issues including how helpful any post was likely to be to the recipient the consistency of the message with the self-image of the ‘sharer’ and the sensitivity of the content. This knowledge could inform key decisions in the development of any future intervention.

Interestingly, Agha-Mir-Salim et al. (2019) found traditional leaflets to be more effective than a Facebook intervention among young adults. They randomly assigned participants aged 18–29 years into one of two conditions: a leaflet arm and a Facebook arm. In the first, participants were posted leaflets concerning skin cancer and ‘sun health’. In the Facebook arm, the same information was provided through daily posts. The leaflet proved the more successful intervention, achieving significantly greater increases in knowledge than the Facebook arm. Technological approaches cannot be guaranteed to be the most effective even among young people.

A second relatively simple use of technology is that of texting. Text messages can be used to remind people of the need to change, provide skills and prompts to engage in change, and record any behavioural change; and have proven effective. In a meta-analysis on data from 19 studies across a range of countries Head et al. (2013) concluded that text messaging was broadly successful in engendering behavioural change. It was most effective for smoking cessation and increasing physical activity, and when personalised to the individuals involved. Four years later, a subsequent meta-analysis by Armanasco et al. (2017) reported similar but slightly differing conclusions. They analysed data from 35 studies and concluded as did Head et al. that text messaging, particularly as an adjunct to other interventions and with a time course of over six months, was effective in both the short- and (to a lesser extent) long-term. More disappointingly, from a psychological perspective, they also noted that interventions that did not use a theoretical basis were more effective than those that did; although of course, this may have been confounded by other factors including the presence of other interventions, time duration and so on. However, their findings that tailoring, targeting and personalisation of texts also appeared to have little influence on outcome challenges many of our so-called 'psychologically sophisticated' approaches to health behaviour change.

Interesting studies within these reviews include that of Naughton et al. (2014), who considered whether personalised text messages could add to the gains made in a primary care smoking cessation intervention. There were no immediate benefits to the texting, but at six-month follow-up those who had received the texts were nearly twice as likely to remain non-smoking than those that attended the smoking cessation groups only. By this time, quit rates in the control group were 9 per cent, while in the text group, 15 per cent of the group were non-smoking. More cautiously, Stanczyk et al. (2014) compared the effects of tailored videos that could be accessed via the internet versus tailored text messages and a comparison condition involving short generic text advice. The negative scenario accessed through the internet was more effective than texts on measures of total number of cigarettes smoked and the percentage of people to quit smoking. Video computer tailoring also resulted in five-fold greater odds of achieving prolonged abstinence rates among smokers with a low readiness to quit.

Analysis of the effectiveness of more complex internet interventions shows both their reach in terms of the number of people they can potentially access and their effectiveness. Schulz et al. (2014), for example, reported a study with over 5,000 participants in which participants received feedback via the internet on how well they complied with the Dutch guidelines for physical activity, vegetable consumption, fruit consumption, alcohol intake, and smoking. They then received tailored motivational feedback on all relevant behaviours, the same feedback but in a sequential flow addressing one behaviour at a time, or no further intervention. The results were presented as a summary statistic of health behaviour, which showed significant gains compared to the control condition for both interventions, and in particular the sequential approach. Importantly, greater gains were made following sequential feedback on difficult to change behaviours of cigarette smoking and alcohol consumption.

In contrast to the previous study, which based its evidence on self-report data, Dallery, Raiff and Grabinski (2013) based their intervention and its outcome on behaviourally validated outcomes. In a much smaller study, they asked participants involved in an online smoking cessation intervention to use internet video to confirm the level of carbon dioxide in their breath was low enough to indicate they were not smoking cigarettes. In their 'contingent reinforcement' condition, those that achieved this criterion received a small monetary voucher. In 'their non-contingent reinforcement condition', participants received the same monetary voucher simply for continuing to take part in the intervention. Validated non-smoking rates during the intervention were 68 and 25 per cent respectively. There were continued gains at 3- and 6-month follow-up, although neither intervention proved superior by this time.

Other exciting approaches that show the flexibility of the internet include an Australian study that allowed people to 'photoage' a photograph of themselves to see how they would look in the future as a smoker and a non-smoker (Burford et al., 2013) and one that asked school students (as part of the intervention) to develop health promoting videos that were 'novel and more effective interventions promoting healthy lifestyle behaviors' for inclusion in a website (Simmons et al., 2013). Web-based approaches can also be used to provide psychologically sophisticated interventions, including direct attempts to use motivational strategies to influence behaviour. Bommelé et al. (2017), for example, found a web-based intervention that included principles from motivational interviewing increased interest and receptivity to health and quit messages in 'hardcore' smokers, although the modest reduction in smoking was not clinically significant.

Technology can be attractive for modern health promoters, but the use of digital approaches does not guarantee success; nor, as we have already seen, are they always more successful than more traditional approaches. The chapter has already identified studies that have found more traditional routes to be more effective than those available through digital methods. And this is not the only relevant evidence. Skov-Ettrup et al. (2014) examined the uptake of a Danish smoking cessation intervention provided through (i) an internet-based smoking cessation program, (ii) 'proactive' telephone counselling (participants had to call the line themselves), (iii) 'reactive' telephone counselling (potential participants were called by counsellors), and (iv) a self-help booklet. The most used intervention was the self-help leaflet, accessed by 84 per cent of participants. Uptake of the other interventions varied;

proactive telephone counselling, 74 per cent; internet, 69 per cent; pro-active telephone counselling, 9 per cent. Cook et al. (2007) compared the effectiveness of a web- and paper-based intervention designed to improve dietary practices, reduce stress and increase physical activity. The web-based programme was more effective than print materials in producing improvements in the areas of diet and nutrition, but the print materials were equally effective in reducing stress or increasing physical activity. Marks et al. (2006) also found that printed materials were more effective than the internet in changing exercise levels.

## SUMMARY

1. Risk factor screening may be of benefit to some individuals, but has not consistently been found to reduce risk for disease. And it may contribute to health anxieties.
2. Motivational interviewing may be more beneficial in both motivating and maintaining health behaviour change, although its impact is not guaranteed.
3. Problem-focused approaches are significantly more effective than those that simply provide health information.
4. Screening for health risk can result in significant anxieties. For some individuals, these may be alleviated by teaching simple coping strategies.
5. Simple media campaigns have proven of little benefit in achieving behavioural change. Augmentation through refining communication based on theories such as the elaboration likelihood model, combing fear and fear reduction messages, appropriate information framing, and audience segmentation may be of benefit.
6. Environmental interventions may also be of benefit. These may provide cues to action or remove cues to unhealthy behaviour; enable healthy behaviour by minimising the costs and barriers associated with it; or maximise the costs of engaging in health-damaging behaviour.
7. Traditional CHD prevention programmes have achieved only modest health gains in the population targeted unless aimed at relatively naïve populations.
8. Peer led interventions have proven more successful across a range of behaviours.
9. The worksite offers a key environment to foster and facilitate health behaviour change.

## Further reading

https://cancercontrol.cancer.gov/brp/research/constructs/implementation-intentions

An internet web page providing details of implementation intentions. Of interest not just because of its content, but its source: the American National Cancer Institute.

https://www.kingsfund.org.uk/topics/public-health

The King's Fund is a UK 'think tank' that considers health policy in a number of arenas. This link takes you to their public health web page, where there is a wealth of information about community and environmental approaches to public health.

White, J. and Bero, L.A. (2004). Public health under attack: the American Stop Smoking Intervention Study (ASSIST) and the tobacco industry. *American Journal of Public Health*, 94: 240–50.

A reminder that the public health agenda is not adopted by all.

Motta, M., Callaghan, T. and Sylvester, S. (2018). Knowing less but presuming more: Dunning-Kruger effects and the endorsement of anti-vaccine policy attitudes. *Social science and Medicine*, 211: 274–281

A partial explanation for the lack of faith in science and vaccination

Hunter, R.F., de la Haye, K., Murray, J.M. et al. (2019). Social network interventions for health behaviours and outcomes: a systematic review and meta-analysis. *PLoS Medicine*, 16: e1002890.

As it says on the tin, a review of the effectiveness of social network interventions.

## YouTube

https://www.youtube.com/watch?v=5zWB4dLYChM

Is this too scary?

https://www.youtube.com/watch?v=MKvKXGMDc5E

Top 10 most effective British adverts . . . or at least according to HelloImaPizza (sic) who provides details of the nature of the ads, but no actual evidence of effectiveness.

https://www.youtube.com/watch?v=IqluZPlako8 and https://www.youtube.com/watch?v=CS6aGKjTnVU

WHO videos on health cities. If you live in a city, then these are a must-see. . .

https://www.youtube.com/watch?v=PZCI_M_n0Ro

Interviews with anti-vaxxers.

Visit the website at **go.pearson.com/uk/he/resources** for additional resources to help you with your study.

# Part II

# Becoming ill

# Chapter 8

# The body in health and illness

## Learning outcomes

In this chapter, we outline the physiology and pathology underpinning a number of chronic diseases, as well as the experiences of people who develop them. This is intended to support the chapters considering the personal and psychological impact of disease on the individual (Chapters 14 and 16 ☛) and their family (Chapter 15 ☛) as well as interventions designed to help people cope more effectively with any symptoms and psychological sequelae of chronic illness they may experience (Chapter 17 ☛). Readers who already have an understanding of the nature of the illnesses described here may choose to skip the chapter. For those that do read the chapter, it should provide an understanding of:

- the basic anatomy and disorders of:
  - the brain
  - the autonomic nervous system
- the basic anatomy, physiology and disorders of:
  - the digestive system
  - the immune system
  - the cardiovascular system
  - the respiratory system

## Bad health costs money!

In the UK, over two million people either have or have recovered from cancer, and a further 3 per cent of the population develops cancer each year. Over 6 per cent of men and 4 per cent of women have heart disease – and treating these individuals costs around £3.5 billion a year, with additional economic costs due to absence from work, caring for others with the disease, and so on adding a further cost of £3.1 billion to the economy. In the USA, an astonishing 17 per cent of individuals within the country have some type of lung disease. A further four per cent have some form of cancer or diabetes, and nearly 7 per cent have heart disease. Together, these chronic diseases cost the nation around $1.5 trillion each year as a consequence of treatment costs and lost productivity. Clearly, chronic diseases are highly prevalent and extremely costly to the nation. Oh, and the personal experience of long-term illness can be emotionally and physically ‘costly’ as well.

## Chapter outline

**This chapter provides an introduction to the key organ systems within the body. Each section considers the basic anatomy and physiology of each system, and describes some of the disease processes and their treatment that may occur within them. Later chapters consider how people can prevent or cope with these diseases, and in some cases the psychological interventions that may help them do this. As well as being a chapter to read on its own, it also forms a reference providing basic information on the illnesses and treatments we refer to in other chapters of the book.**

**We start by examining two systems that influence the whole body:**

1. **the brain and autonomic nervous system**
2. **the immune system.**

**We then go on to examine three other organ systems:**

1. **the digestive system**
2. **the cardiovascular system**
3. **the respiratory system.**

# The behavioural anatomy of the brain

The brain is an intricately patterned complex of nerve cell bodies. It is divided into four anatomical areas (see Figures 8.1 and 8.2):

1. *Hindbrain*: contains the parts of the brain necessary for life – the medulla oblongata, which controls blood pressure, heart rate and respiration; the reticular formation, which controls alertness and wakefulness; and the pons and cerebellum, which integrate muscular and positional information.
2. *Midbrain*: contains part of the reticular system and both sensory and motor correlation centres, which integrate reflex and automatic responses involving the visual and auditory systems and are involved in the integration of muscle movements.
3. *Forebrain*: contains key structures that influence mood and behaviour, including:
   - *Thalamus*: links the basic functions of the hindbrain and midbrain with the higher centres of processing, the cerebral cortex. Regulates attention and contributes to memory functions. The portion that enters the limbic system (see below) is involved in the experience of emotions.
   - *Hypothalamus*: regulates appetite, sexual arousal and thirst. Also appears to have some control over emotions.
   - *Limbic system*: (Figure 8.3) a series of structures including a linked group of brain areas known as the Circuit of Papez (the hippocampus–fornix–mammillary bodies–thalamus–cingulate cortex–hippocampus). The hippocampus–fornix–mammillary bodies circuit is involved in memory. The hippocampus is one site of interaction between the perceptual and memory systems. A further part of the system, known as the amygdala, links sensory information to emotionally relevant behaviour, particularly responses to fear and anger. It has been called the 'emotional computer' because of its role

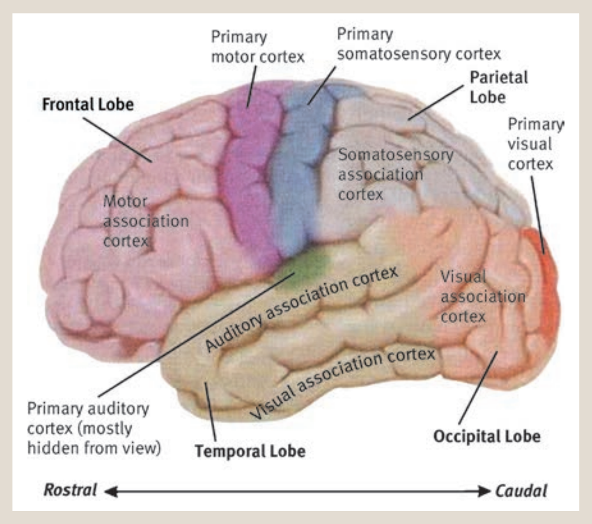


**Figure 8.1** A cross-section through the cerebral cortex of the human brain

*Source*: Carlson, N. (2007), © 2007, reproduced by permission of Pearson Education, Inc.

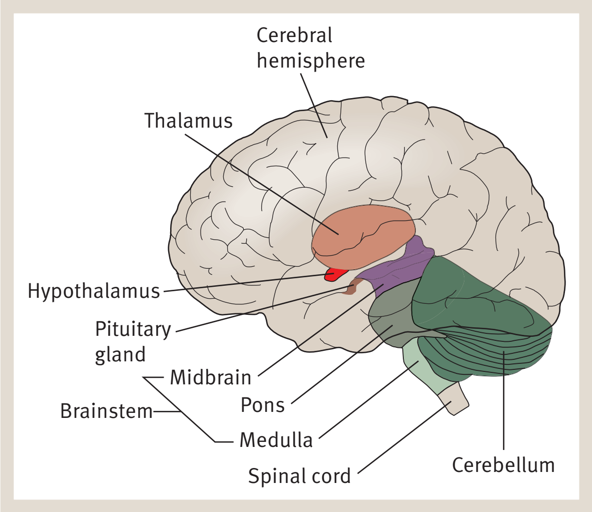


**Figure 8.2** A lateral view of the left side of a semi-transparent human brain with the brainstem 'ghosted' in

*Source*: Carlson, N. (2007), © 2007, reproduced by permission of Pearson Education, Inc.

in coordinating the process that begins with the evaluation of sensory information for significance (i.e. threat) and then controls the resulting behavioural and autonomic responses (see below).

4. *Cerebrum*: the most recently evolved part of the brain includes:

   - *Basal ganglia*: responsible for complex motor coordination.

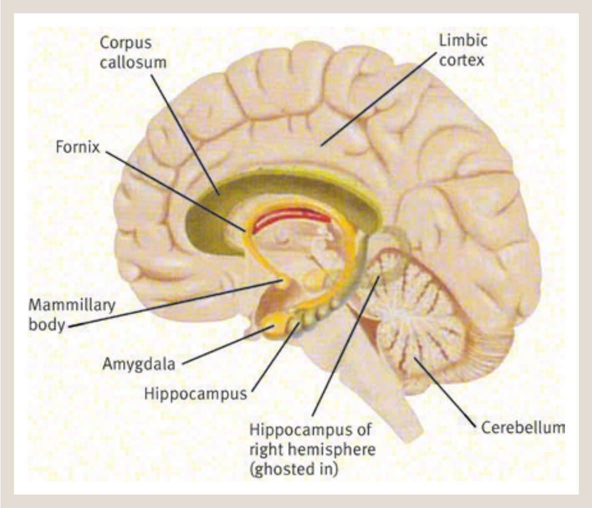


**Figure 8.3** The major components of the limbic system. All of the left hemisphere apart from the limbic system has been removed.

*Source*: Carlson, N. (2007), © 2007, reproduced by permission of Pearson Education, Inc.

   - *Cortex*: the convoluted outer layer of grey matter comprising nerve cell bodies and their synaptic connections. It is divided into two functional hemispheres linked by the *corpus callosum*, a series of interconnecting neural fibres, at its base and is divided into four lobes: frontal, temporal, occipital and parietal:

   - *The frontal lobe* has an 'executive' function, as it coordinates a number of complex processes, including speech, motor coordination and behavioural planning. The frontal lobes also influence motivation. The pre-frontal lobes are connected to the limbic system via the thalamus and motor system within the cortex. Links between the pre-frontal cortex and the limbic system are activated during rewarding behaviour.

   - *The temporal lobes* have a number of functions. In right-handed people, at the risk of oversimplification, the main language centre is generally located in the left hemisphere, and visuo-spatial processing is located in the right. In left-handed individuals, there is less localisation within the hemispheres. The temporal lobes are also involved in the systems of smell and hearing. They integrate the visual experience with those of the other senses to make meaningful wholes. The temporal lobes have an important role in memory and contain systems that preserve the record of conscious experience.

Finally, they connect to the limbic system and link emotions to events and memories.

- *The occipital and parietal lobes* are involved in the integration of sensory information. The occipital lobe is primarily involved in visual perception. Links to the cortex permit interpretation of visual stimuli.

## Problems of neurological functioning

There are many causes of neurological dysfunction, including brain trauma and neural degeneration as a consequence of a range of types of dementia. However, the neurological problem most frequently encountered by health psychologists is variously known as a ‘stroke’ or, more technically, a cerebrovascular accident (CVA). The primary cause of a CVA is the disruption of blood supply to part of the brain, causing the death of neurons previously provided with oxygen and other nutrients by the affected blood vessel(s). This can result from one of two causes: a clot (thrombosis) developing in, and blocking the blood flow through a blood vessel, or rupture in a blood vessel’s wall causing a bleed into the neural tissue. A temporary restriction of blood supply which may also result in the short-term and reversible experience of symptoms similar to a CVA is referred to as a transient ischaemic attack (TIA) (ischaemia meaning lack of blood supply).

The location of the stroke within the brain will determine the type of symptoms experienced. However, there are now some internationally acknowledged signs of the onset of a stroke and how to respond to them:

- sudden numbness or weakness in the face, arm, or leg, especially on one side of the body;
- sudden confusion, trouble speaking, or difficulty understanding speech;
- sudden trouble seeing in one or both eyes;
- sudden trouble walking, dizziness, loss of balance, or lack of coordination;
- sudden severe headache with no known cause

If these symptoms are identified, the acronym F.A.S.T. guides a response:

**F – Face:** Ask the person to smile. Does one side of the face droop?

**A – Arms:** Ask the person to raise both arms. Does one arm drift downward?

**S – Speech:** Ask the person to repeat a simple phrase. Is their speech slurred or strange?

**T – Time:** If you observe any of these signs, call for emergency medical help immediately.

If the stroke is a result of a blood clot, immediate treatment using thrombolytic drugs can ‘dissolve’ the clot and reduce or eliminate any neural damage. Delay will negatively influence the likely effectiveness of such treatment.

As a rough and ready guide, one rule of thumb is that strokes in the left hemisphere are likely to cause problems in language and communication as they may impact on the language centres in the right side of the brain in right-handed individuals. Those in the right hemisphere, will result in problems of muscular weakness or even paralysis of limbs as the motor cortex is often involved. However, the long-term symptoms can be more subtle than this crude dichotomy (which also does not apply to left-handed individuals), and include a whole dictionary of symptoms, including: **hemiplegia** or **hemiparesis**, **dysphasia** and **dysarthria**, **aphasia** and **apraxia**, **visual field loss**, and **hemianopia**. The affected individual may

hemiplegia
inability to move one side of the body.

hemiparesis
weakness on one side of the body.

dysphasia
language disorder marked by deficiency in the generation of speech, and sometimes also in its comprehension.

dysarthria
difficulty speaking caused by problems controlling the muscles used in speech.

aphasia
inability (or impaired ability) to understand or produce speech, as a result of brain damage.

apraxia
inability to perform particular purposive actions.

visual field loss
loss of *part* of the usual field of vision. It does not involve blindness of either one eye or both.

hemianopia
blindness in half the visual field of one or both eyes.

also experience problems in learning, concentration, and recall from long- or short-term memory, fatigue, and inappropriate emotional responses. While any one individual will only experience some of these symptoms, the condition can clearly be problematic in the long-term and patients may require significant input from a range of health professionals including speech therapists, neuropsychologists, and physiotherapists to aid their long-term recovery.

## The autonomic nervous system

The autonomic nervous system is responsible for control over levels of activity in key organs and organ systems in the body. Many organs have some degree of control over their functioning. The heart, for example, has an intrinsic rhythm of 110 beats per minute. However, this level of activity may not be appropriate at all times. The heart may have to beat more at times of exercise, less at times of rest. The autonomic nervous system overrides local control to provide a higher level of coordinated control across most of the bodily systems in response to the varying demands being placed on the body. Its activity is controlled by a number of brain areas, the most important of which is the hypothalamus. The hypothalamus receives information about the demands being placed on the body from a variety of sources, including:

- information about skin temperature from the reticular formation in the brainstem;
- information about light and darkness from the optic nerves;
- receptors in the hypothalamus itself provide information about the ion balance and temperature of the blood.

The hypothalamus also has links to the cortex and limbic systems of the brain, which are involved in the processing of cognitive and emotional demands. This allows the autonomic system to respond to psychological factors as well as physical demands being placed on the body. Accordingly, the autonomic nervous system can initiate sweating in high temperatures, increase blood pressure and heart rate during exercise, and also make us physiologically responsive at times of stress, distress or excitement (we discuss these responses further in Chapters 11 and 13 ☛).

The autonomic nervous system controls these varying levels of activity through two opposing networks of nerves (see Figure 8.4):

1. the **sympathetic nervous system**: involved in activation and arousal – the fight–flight response;
2. the **parasympathetic nervous system**: involved in relaxation – the rest–recover response.

Both sets of nerves arise in an area in the brainstem area known as the medulla oblongata (which is linked to the hypothalamus). From this, they pass down the spinal cord to various **synapses**, where they link to a second series of nerves that are linked to all the key body organs, including the heart, arteries and muscles (Figure 8.4). For the sympathetic arm, the **neurotransmitter** involved at the synapse between the spinal cord nerves and the nerve to the target organ is acetylcholine. Activity at the synapse between this second nerve and the end organ mainly involves a neurotransmitter known as noradrenalin, and to a lesser extent adrenalin (confusingly, also often called norepinephrine and epinephrine). The parasympathetic system uses acetylcholine at both synapses. The activity in each of the organs depends on the relative activity in the sympathetic and parasympathetic nervous systems. When activity in the sympathetic system dominates, the

**sympathetic nervous system**

the part of the autonomic nervous system involved in mobilising energy to activate and maintain arousal (e.g. increased heart rate).

**parasympathetic nervous system**

arm of the autonomic nervous system that is responsible for rest and recuperation.

**synapse**

junction between two neurons or between a neuron and target organ – nerve impulses cross a synapse through the action of neurotransmitters.

**neurotransmitter**

a chemical messenger (e.g. adrenaline, acetylcholine) used to communicate between neurons and other neurons and other types of cell.

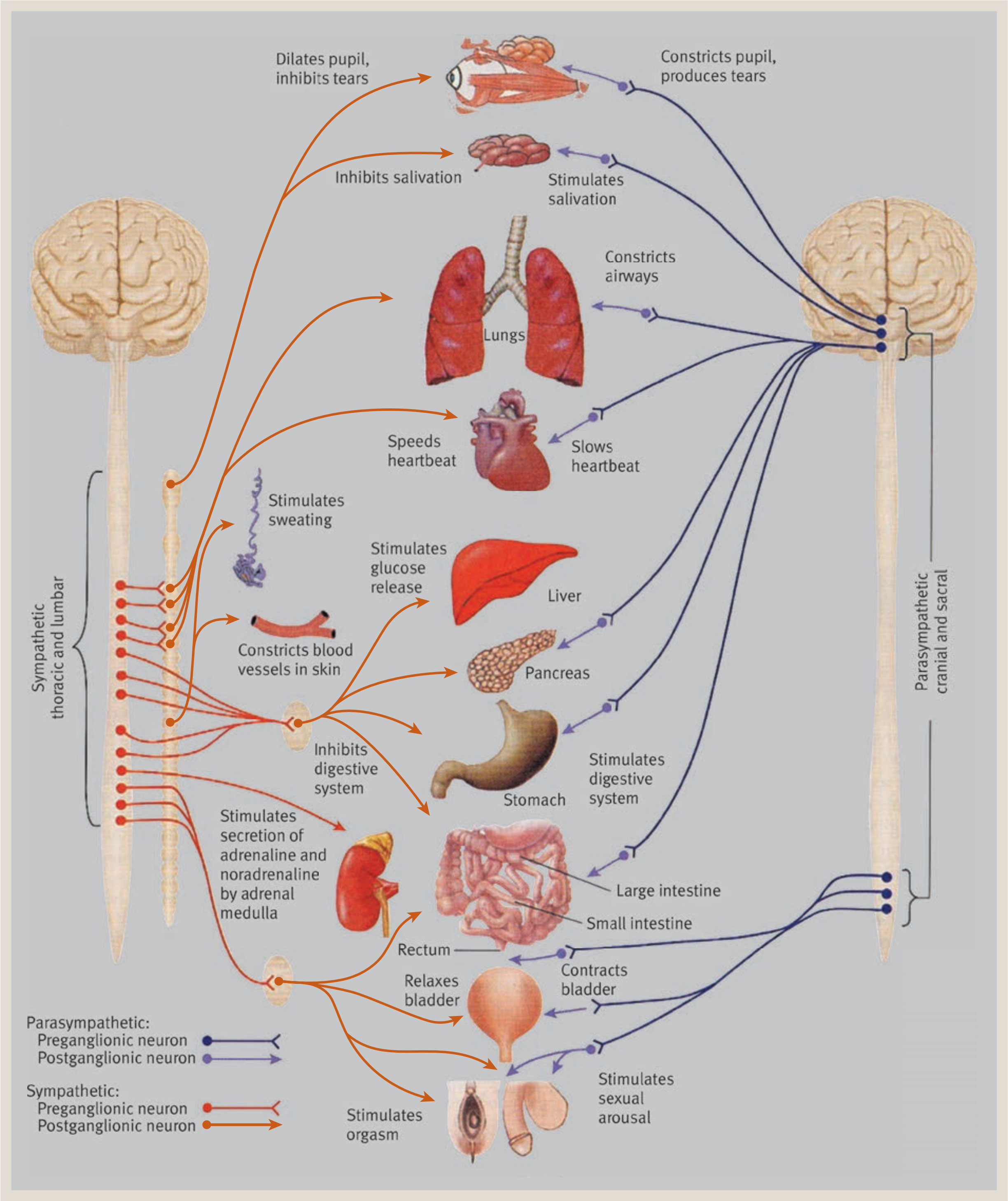


**Figure 8.4** The autonomic nervous system, with the target organs and functions served by the sympathetic and parasympathetic branches

*Source*: Carlson, N. (2007), © 2007, reproduced by permission of Pearson Education, Inc.

**Table 8.1** Summary of responses of the autonomic nervous system to sympathetic and parasympathetic activity

| Structure | Sympathetic stimulation | Parasympathetic stimulation |
|---|---|---|
| Iris (eye muscle) | Pupil dilation | Pupil constriction |
| Salivary glands | Saliva production reduced | Saliva production increased |
| Heart | Heart rate and force increased | Heart rate and force decreased |
| Lung | Bronchial muscle relaxed | Bronchial muscle contracted |
| Stomach | Peristalsis reduced | Gastric juice secreted; motility increased |
| Small intestine | Motility reduced | Digestion increased |
| Large intestine | Motility reduced | Secretions and motility increased |
| Liver | Increased conversion of glycogen to glucose | |
| Kidney | Decreased urine secretion | Increased urine secretion |
| Bladder | Wall relaxed | Wall contracted |
| | Sphincter closed | Sphincter relaxed |

body is activated: when the parasympathetic system is dominant, the body is resting and relatively inactive, allowing basic functions such as digestion and the production of urine to occur more easily (see Table 8.1).

## Endocrine processes

The activity initiated by the sympathetic nervous system is short-lived. A second system is therefore used to provide longer-term arousal. This system uses **endocrine glands**, which communicate with their target organs by releasing hormones into the bloodstream. The endocrine glands that extend the activity of the sympathetic nervous system are the **adrenal glands**, which are situated above the kidneys. These have two functional areas, each of which is activated in different ways:

1. the centre or *adrenal medulla*;
2. the surrounding tissues, known as the *adrenal cortex*.

The adrenal medulla is innervated by the sympathetic nervous system. Activity in this system stimulates the adrenal medulla to release the hormonal equivalent of the neurotransmitter noradrenaline into the bloodstream, in which it is transported to the organs in the body. Receptors in the target organs respond to the hormone and maintain their activation. Because the hormone can be released for a longer period than the neurotransmitter, this extends the period of activation.

A second activating system involves the pituitary gland, the activity of which is also controlled by the hypothalamus. This lies immediately under the brain (see Figure 8.2), and when stimulated by the hypothalamus, it releases a number of hormones into the bloodstream, the most important of which is adrenocorticotrophic hormone (ACTH). When the ACTH reaches the adrenal cortex, it causes it to release hormones known as **corticosteroids**, the most important of which is **cortisol** – also known as hydrocortisone. Cortisol increases the availability of energy stores and fats to fuel periods of high physiological activity. It also inhibits inflammation of damaged tissue. The sympathetic nervous system is central to our stress response, and we discuss this again in Chapter 11 ☛. Thus, the nervous system can be considered to have two different routes of influence. The activation route via the sympathetic nervous system and adrenal medulla (known

### endocrine glands

glands that produce and secrete hormones into the blood or lymph systems; includes the pituitary and adrenal glands, and the islets of Langerhans in the pancreas; these hormones may affect one organ or tissue, or the entire body.

### adrenal glands

endocrine glands, located above each kidney; comprise the cortex, which secretes several steroid hormones, and the medulla, which secretes noradrenaline.

### corticosteroids

powerful anti-inflammatory hormones (including cortisol) made naturally in the body or synthetically for use as drugs.

### cortisol

a stress hormone that increases the availability of energy stores and fats to fuel periods of high physiological activity; it also inhibits inflammation of damaged tissue.

as the sympathomedullary pathway: SAM) and the processes that support activation and cellular repair via the hypothalamus, pituitary, and adrenal cortex (known as the HPA axis).

# The immune system

## Components of the immune system

The immune system provides a variety of protective mechanisms that respond to attacks from bacteria, viruses, infectious diseases and other sources (collectively known as **antigens**) from outside the body. In this section, we briefly describe the role of different elements of the immune system. We then go on to look at the links between them and how they combine to combat invading pathogens and the development of cancers.

A number of organs and chemicals form the front line of the system. These include:

- *Physical barriers*: provided by the skin.
- *Mechanical barriers*: cilia (small hairs in the lining of the lungs) propel pathogens out of the lungs and respiratory tract – coughs and sneezes achieve the same goal more dramatically. Tears, saliva and urine also push pathogens out of the body.
- *Chemical barriers*: acid from the stomach provides an obvious chemical barrier against pathogens. Sebum, which coats body hairs, inhibits the growth of bacteria and fungi on the skin. Saliva, tears, sweat and nasal secretions contain lysozyme, which destroys bacteria. Saliva and the walls of the gastrointestinal tract also contain an **antibody** known as immunoglobulin A (IgA).
- '*Harmless pathogens*': a variety of bacteria live within the body and have no harmful effects on us. However, they defend their territory and can destroy other bacteria that invade it.
- *Lymph nodes*: secondary organs at or near possible points of entry for pathogens. This system includes the tonsils, Peyer's patches in the intestines, and appendix. They contain high levels of **lymphocytes** (see below), ready to attack any invading pathogens.

As well as these relatively static defences against attack, there are a number of cells that circulate around the body. This can be through the circulatory system or a parallel system known as the lymphatic system. This carries a fluid called lymph and transports cells important to the destruction of antigens to the sites of cellular damage and the waste products of their destruction away from them.

Two groups of cells in the circulatory and lymphatic systems provide protection against a variety of pathogens. **Phagocytes** (sometimes called white blood cells) circulate within the circulatory system. They are created in the bone marrow and attract, adhere to and then engulf and destroy antigens in a process known as phagocytosis. The immune system has a number of phagocytes, including:

- *Neutrophils* have a short life of a few hours to days. They provide the major defence against bacteria and the initial fight against infection by engulfing and digesting them.
- *Macrophages* are long-lived and are best at attacking dead cells and pathogens capable of living within cells. Once a macrophage destroys a cell, it places some of its own proteins on its surface. This allows other immune cells to identify cells as invaders and to attack them.

antigens

a collective name for a variety of challenges to our health and immune system, including bacteria and viruses.

antibodies

immunoglobulins produced in response to an antigen.

lymphocyte

a type of white blood cell. Lymphocytes have a number of roles in the immune system, including the production of antibodies and other substances that fight infection and disease; includes T and B cells.

phagocyte

an immune system cell that can surround and kill micro-organisms and remove dead cells; phagocytes include macrophages.

A second group of cells known as lymphocytes circulate in the blood (where they are also known as white blood cells) and lymph system. These include **T cells** and **B cells**:

- Cytotoxic T cells bind on to antigens, including virus-infected cells and tumour cells. They form pores in the target cell's plasma membrane, allowing ions and water to flow into the target cell, making it expand, then collapse and die.
- Helper T cells trigger or increase an immune response. They identify and bind to antigens, then release chemicals known as cytokines that stimulate the proliferation of cytotoxic T and plasma B cells (see below). Helper T cells are also known as **CD4+ cells** because of their chemical structure. Accordingly, helper T cells and cytokines are central to the immune response as they are responsible for increasing the body's initial immune response to one which can effectively respond to the invading antigens or cancer cells.
- Plasma B cells destroy antigens by binding to them and making them easier targets for phagocytes. They attack antigens in the blood system before they enter body cells.
- Memory B cells live indefinitely in the blood and lymphatic systems. They result from an initial attack by a novel antigen. In their initial response to such attacks, memory B cells 'learn' the chemical nature of the antigens they attack and are able to deal with them more effectively should they encounter them again.

**Natural killer (NK) cells** form third group of attacking cells. They move in the blood and attack cancer cells and virus-infected body cells.

## Central nervous system links with the immune system

The immune system is intimately linked to the central nervous system. The influence of these two interacting systems affects the development and activity of phagocytes, B, T and NK cells. Lymphocytes have adrenaline and cortisol receptors, which are affected by hormones from both the adrenal cortex and medulla (see above). The influence of these neurotransmitters and hormones is complex. Increased adrenalin in response to short-term stress can stimulate the spleen to release phagocytes into the bloodstream and increase NK cell counts but decrease the number of T cells. Cortisol release decreases the production of helper T cells and ingestion of cells by macrophages.

Catecholamines (adrenalin and noradrenalin) also influence the degree of inflammation associated with an immune response through their influence on cytokine production. A type of cytokine known as interleukins are involved in the regulation of inflammation and cellular repair, with interleukins which both trigger (interleukin 6: IL-6) and control (IL-10) inflammation. Although inflammation is generally seen as a 'bad' thing, in this case it can be a positive process, at least in the short term, as it clears out dead cells and tissues damaged from the original insult and initiates tissue repair. Pro- and anti-inflammatory cytokines are produced by many cells in the body; for example cytokines are produced by many cells in the immune system, including B and T-helper cells. Their production is regulated by glucocorticoids and catecholamines. Catecholamines increase pro-inflammatory cytokine production, glucocorticoids are known to inhibit it, with consequences of increasing susceptibility to infection or impairing wound healing (Gouin et al., 2008; Walburn et al., 2009). It is now generally accepted that there is communication both within and between the neuroendocrine and immune systems, with the brain providing an immuno-regulatory role. These issues are complex and differ over the time course of stress and the nature of the stressor. However, it is generally recognised that chronic stress significantly impairs the effectiveness of the immune system, leaving us less able to ward off infection (see Chapter 11 ☛ for further discussion of this issue).

**T cell**

a cell that recognises antigens on the surface of a virus-infected cell, binds to that cell and destroys it.

**B cell**

a form of lymphocyte involved in destruction of antigens. Memory B cells provide long-term immunity against previously encountered pathogens.

**CD4+ cells**

otherwise known as helper T cells, these are involved in the proliferation of cytotoxic T cells as part of the immune response; HIV infection impairs their ability to provide this function.

**natural killer (NK) cells**

cells that move in the blood and attack cancer cells and virus-infected body cells.

# Immune dysfunction

## Human immunodeficiency Virus infection

The human immunodeficiency virus (HIV) is the cause of a potentially fatal condition known as Acquired Immune-Deficiency Syndrome (AIDS). The virus belongs to a subgroup of viruses known as ‘slow viruses’, which have a long interval between initial infection and the onset of serious symptoms – potentially up to ten years and beyond. The virus affects the T helper (CD4+) cells. In response to a virus or other pathogens, healthy CD4+ cells replicate and send messages to B and T cells to also replicate and attack the pathogen. When infected with HIV, CD4+ cells still replicate in response to pathogens, but the replicated CD4+ cells are infected with the virus, are unable to activate their target B and T cells, and eventually die. Initially, the non-infected CD4+ cells still provide an effective response against pathogens. However, over time, proliferation of infected CD4+ cells in response to pathogens results in an increase in infected CD4+ cells in circulation. These will eventually die, but before doing so may bind with healthy CD4+ cells, resulting in their death. In addition, the immune system may recognise the virus-laden cells as invasive and begin to attack its own CD4+ cells. Together, these processes result in a gradual reduction in the number of circulating CD4+ cells, reducing the immune system’s ability to defend itself effectively against viruses, bacteria and some cancers. When the CD4+ cell count falls below 500/mm$^3$, approximately half the immune system reserve has been destroyed. At this point minor infection such as cold sores and fungal infections begin to appear. Once the CD4+ cell count falls below 200/mm$^3$, life-threatening opportunistic infections and cancers typically occur. AIDS, the end point of HIV disease, occurs when the CD4+ cell count is less than 200/mm3 or when the individual develops potentially life-threatening infections such as pneumonia or cancers such as **Kaposi’s sarcoma**.

Kaposi’s sarcoma

a malignant tumour of the connective tissue, often associated with AIDS. The tumours consist of bluish-red or purple lesions on the skin; they often appear first on the feet or ankles, thighs, arms, hands and face.

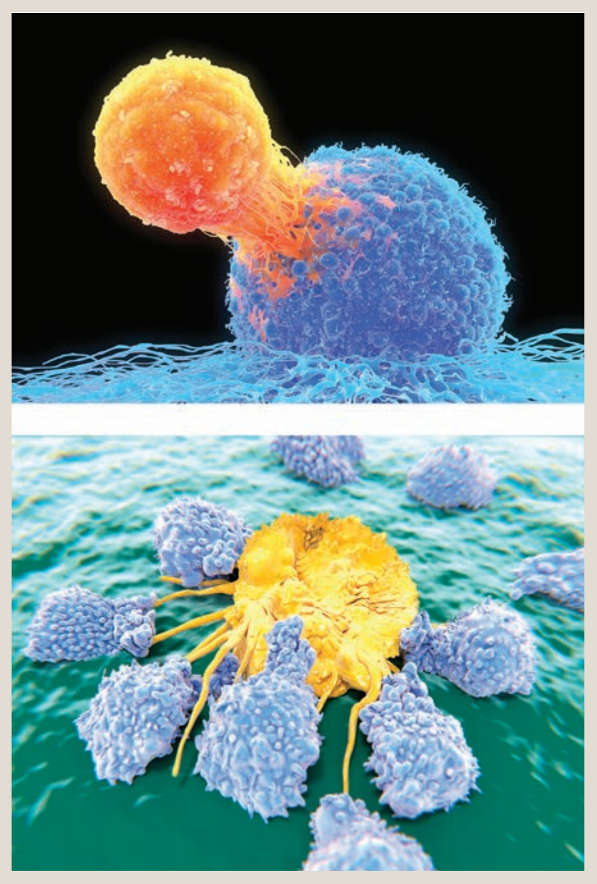


**Photo 8.1 and 8.2** Here we see two cells, a virus and cancer cell, being attacked and either engulfed by B cells (8.1) or rendered inert by NK cells (8.2)

*Source*: Roger Harris/Science Photo Library/Getty Images and Juan Gaertner/Science Photo Library/Getty Images.

Treatment for HIV infection includes a number of drug types including:

- *Reverse transcriptase inhibitors*: (Nucleoside reverse transcriptase inhibitors (NRTIs or ‘nukes’ and Nucleotide reverse transcriptase inhibitors (NtRTIs and non-nucleoside reverse transcriptase inhibitor (NNRTI). HIV uses reverse transcriptase to copy its genetic material from RNA to DNA in order to replicate. Reverse transcriptase inhibitors disrupt the process and thereby suppress the virus making copies of itself.
- *Protease inhibitors*: HIV injects its genetic material into CD4+ immune cells, which proliferate at times of infection. Protease inhibitor drugs block the action

of protease enzymes which are central to this process and prevent the virus from multiplying.

- *Fusion inhibitors*: These interfere with the virus's ability to fuse with the cellular membrane of other CD4+ cells, blocking entry into the host cell.
- *Integrase inhibitors*: Integrase allows the DNA of the virus to merge with the DNA of the T cells once injected. Preventing this stops the proliferation of HIV infected T cells, and hence the risk for AIDS.

Treatment guidelines developed by the British HIV Association recommend that everyone with HIV, regardless of their CD4+ count, should start treatment immediately, usually with three anti-HIV drugs. This would typically involve a combination of two NRTIs and either a protease inhibitor, an NNRTI, or an integrase inhibitor. Some of these drugs can now be combined in multiple mechanism drugs such as Truvada or Stribild. These drugs do not cure HIV infection or AIDS. They can suppress the virus to undetectable levels but are unable to completely eliminate HIV from the body. Accordingly, infected individuals need to take them for life. More positively, these drugs can bring levels of HIV infection to unmeasurable levels; sufficient to prevent transmission of the virus through unprotected sex. In addition, they provide significant life extension, with people infected with HIV living between 60 (in Rwanda) and 89 (in Canada) per cent of the typical lifespan (Wandeler, Johnson and Egger, 2016).

## Autoimmune conditions

The immune system is able to identify cells that are part of the body ('self') and those that are 'non-self': antigens, developing cancers, and so on. On occasion, this process breaks down and the immune system treats cells within the body as non-self and begins to attack them. This can result in a number of **autoimmune conditions**, including diabetes, rheumatoid arthritis and multiple sclerosis.

### Diabetes

Two types of **diabetes** have been identified. In **type 1 diabetes**, the body does not produce sufficient insulin within the islets of Langerhans in the **pancreas**. Its onset is frequently triggered by an infection, often by one from the Coxsackie virus family. This virus expresses a protein similar in structure to an enzyme involved in the production of insulin, and the immune response to this virus can also destroy the insulin-producing cells within the pancreas. Insulin normally attaches itself to glucose molecules in the circulatory system, permitting it to be taken up by the various body organs which need it to provide them with energy. Without insulin, these glucose molecules cannot be absorbed, leading to high levels of glucose within the blood which the body cannot use. This can lead to a life-threatening coma known as diabetic ketoacidosis, which requires hospitalisation and immediate treatment to avoid death. Less dramatic symptoms include increased thirst and urination, constant hunger, weight loss, blurred vision and extreme fatigue.

Treatment typically involves between one and four injections of insulin a day, meal planning to avoid sudden peaks of glucose being released into the bloodstream, weight control, and exercise. Treatment is a balancing act, aimed at achieving appropriate levels of circulating blood glucose. Too much food and/or too little insulin can result in ketoacidosis. Too little food and/or too much insulin can result in a condition known as hypoglycaemia,

**autoimmune conditions**
a group of diseases, including type 1 diabetes, Crohn's disease and rheumatoid arthritis, characterised by abnormal functioning of the immune system in which it produces antibodies against its own tissues – it treats 'self' as 'non-self'.

**diabetes (type 1 and 2)**
a lifelong disease marked by high levels of sugar in the blood and a failure to transfer this to organs that need it. It can be caused by too little insulin (type 1), resistance to insulin (type 2), or both.

**type 1 diabetes**
see **diabetes**.

**pancreas**
gland in which the islets of Langerhans produce insulin; also produces and secretes digestive enzymes; located behind the stomach.

characterised by symptoms including a period of confusion and irritability, followed by a fairly rapid loss of consciousness. Immediate treatment is to give oral glucose where possible, or intravenously if the individual has lost consciousness. Good day-to-day control over diabetes reduces but does not obviate long-term complications including poor circulation which can lead to loss of sight, heart disease, skin ulcers, loss of limbs and nerve damage.

A second form of the condition is known as **type 2 diabetes**. In this, the body produces sufficient insulin (or close to sufficient), but the cells that take up the glucose- insulin molecules become 'resistant', and no longer absorb them. Type 2 diabetes often develops later in life, and is associated with obesity – a person's chances of developing type 2 diabetes roughly increases by 4 per cent for every pound of excess weight. The symptoms of type 2 diabetes develop gradually, and their onset is not as sudden as in type 1 diabetes. They may include fatigue or nausea, frequent urination, unusual thirst, weight loss, blurred vision, frequent infections and slow healing of wounds or sores. Some people have no symptoms.

According to the UK National Institute for Health and Care Excellence (NICE, 2017a), first-line treatment for type 2 diabetes involves weight loss and exercise – although many people find it hard to adhere to such regimens (García-Pérez et al., 2013). Second-line treatment involves treatment with oral medication designed to variously stimulate the beta cells in the pancreas to release more insulin, decrease the amount of glucose produced by the liver and enhance the effectiveness of naturally produced insulin, and lower glucose levels by blocking the breakdown of starches in the gut. We discuss the impact of diabetes on the individual and family in Chapter 15 ☛ and interventions designed to increase adherence to insulin and appropriate behavioural change in Chapter 17 ☛.

## Rheumatoid arthritis

**Rheumatoid arthritis** (RA) may be triggered by viruses in individuals with a genetic tendency for the disease. It is a systemic disease that affects the entire body (and can impact on internal organs including lungs, heart and eyes) and is characterised by inflammation of the membrane lining the joints (the synovium). Any joint may be affected, but the hands, feet and wrists are the most frequently involved. It is a chronic, episodic condition, with 'flare-ups' and periods of remission. During flare-ups, people with the condition experience significant pain, stiffness, warmth, redness and swelling in affected joints – as well as fatigue, loss of appetite, fever and loss of energy. Over the long term, inflammatory cells in the synovium release enzymes that digest bone and cartilage, leading to joints losing their shape and alignment, and pain and restricted movement within the joint. Rheumatoid arthritis is more common in women than in men and affects relatively young people: the age of onset is usually between 25 and 50 years.

There is no known cure for RA although its symptoms can be managed. The goal of treatment is to reduce joint inflammation and pain, maximise joint function, and prevent joint destruction and deformity. Treatment recommended by NICE (2020) involves both medication and self-care: rest, joint strengthening exercises and joint protection. Two types of medications are used: fast-acting 'first-line drugs' and slow-acting 'second-line drugs'. First-line drugs, such as aspirin and cortisone (corticosteroids), are used to reduce pain and inflammation. Slow-acting second-line drugs, such as gold, methotrexate and hydroxychloroquine promote disease remission and prevent progressive joint destruction. NICE also recommend a range of non-medical interventions including physiotherapy to maintain joint function and strategies including cognitive behavioural therapy and mindfulness to help cope with any associated emotional problems.

As can be seen in the example of Mrs K (see Case history 1 box) people with RA may also benefit from a number of aids to help them engage in many everyday behaviours. Mrs K recounts a typical day which may not be different to many people's day, but which is characterised by small (and not so small) frustrations due to her condition. We examine the impact of arthritis on the individual and their family in Chapters 14 and 15 ☛, treatment of the pain associated with arthritis in Chapter 16 ☛, and self-management programmes to help people minimise the negative impact of arthritis on their lives in Chapter 17 ☛.

**type 2 diabetes**

see **diabetes**.

**rheumatoid arthritis**

a chronic autoimmune disease with inflammation of the joints and marked deformities.

## Case history 1: Mrs K

I am a 39-year-old wife and mother of two young children. I have had severe rheumatoid arthritis for nearly six years. This has caused deformities in my hands and feet. My fingers are gnarled. My wrists have nearly fused. My toes have bent upwards. My knees and many of the small joints of my knuckles are swollen.

I am usually very stiff when I wake up, so I get up slowly. After sitting at the side of the bed, I stand slowly, then slowly walk to the kitchen to prepare breakfast and school lunches for my children. Because my grip has been impaired with my deformities, I use a knife with an oversized grip handle to make sandwiches. I use a lid gripper pad to open jars. I take my tablets with my breakfast.

After breakfast, it's time for my morning washing routine. I have a raised toilet seat to avoid straining my joints sitting down and getting up. I shower while waiting for the morning tablets to start working. Washing my hair is difficult with my hands and I have adapted a scrubbing brush to help me wash it. I am careful getting in and out of the shower because the instability of my legs puts me at risk of falling.

Getting dressed is not easy. I am too clumsy to use buttons, so most of my shirts are pullover or have velcro attachments. My bra can be fastened in front and reversed or I ask my husband to fasten it for me.

Most of my trousers have elastic waistbands and do not require buttoning or zipping. My shoes are especially wide and I usually wear running shoes for comfort. I dress for comfort – not for 'fashion'!

I drive the kids to school. Getting into and out of the car is painful and slow. I have a special key enlarger attachment for my car and house keys, which makes it easier to turn them. I can drive, but it makes my wrists hurt.

I try to exercise every day. I start with stretching exercises, then either ride a stationary bike or go on a walk. Once a week, I go for a swim. Exercise makes me feel good and gives me a sense of control over my body. Housework also always needs doing. I make good use of attachments to the vacuum cleaner that help me get to places that are hard to reach. Our door handles are levers instead of knobs so that it is easier for me to turn them. I can't do the ironing. When I cook, I use special grippers to hold the handles of pots and pans, and an electric can opener.

At bedtime, undressing can be as challenging as dressing. My husband frequently assists me with the undressing. My wrists are frequently painful by the evening, so I strap on my wrist splints before reading a few chapters of my novel and calling it a night.

## Multiple sclerosis

**Multiple sclerosis** (MS) is a neurological condition involving repeated episodes of inflammation of the central nervous system (brain and spinal cord). This results in the slowing or blocking of the transmission of nerve impulses. As this may occur in any part of the brain or spinal cord, symptoms can differ markedly across individuals, and include loss of limb function, loss of bowel and/or bladder control, blindness due to inflammation of the optic nerve, and cognitive impairment. Muscular spasticity is a common feature, particularly in the upper limbs. Around 95 per cent of people with MS experience debilitating fatigue, which can be so severe that about 40 per cent of people with the condition are unable to engage in sustained physical activity, while 30 to 50 per cent require walking aids or a wheelchair for mobility. During acute symptomatic episodes, patients may be hospitalised.

The course of MS differs across individuals. Twenty per cent of people with the condition have a benign form of the disease in which symptoms show little or no progression after the initial episode. A few people experience malignant MS, resulting in a swift and relentless decline, with significant disability or even death occurring shortly after disease onset. Onset of this type of MS is usually after the age of 40 years. The majority of people have an episodic condition, known as remitting–relapsing MS, with acute flare-ups followed by periods of remission. Each flare-up, however, is usually followed by a failure to recover to previous levels of function, resulting in a slowly deteriorating condition. Death is usually due to complications of MS including choking, pneumonia and renal failure. As well as physical problems, nearly half the people with MS experience some degree of cognitive impairment and memory problems. In addition, around

**multiple sclerosis**
a disorder of the brain and spinal cord caused by progressive damage to the myelin sheath covering of nerve cells.

half will be clinically depressed at some time during the course of the illness (Patten, Marrie and Carta, 2017). Whether this is a direct result of neuronal damage or a reaction to the experience of the disease is not clear. It may, of course, be both.

One chemical within the immune system, called gamma-interferon, is particularly implicated in MS. This stimulates production of cytotoxic T cells, which are responsible for attacking and destroying diseased or damaged body cells. In MS, the activated cytotoxic T cells wrongly identify the **myelin sheath** of nerve cells within the brain and spinal column as ‘non-self’, and attempt to destroy it. Viral infections may act as a trigger to the production of gamma-interferon, and the onset of MS may follow a viral infection.

Ms F (see ‘Case history 2’ box) provides an insight into what it feels like to have MS. At the time of our talk she was taking antidepressants for her depression and, as you will read, was having problems coming to terms with her illness.

**myelin sheath**

a substance that contains both protein and fat (lipid) and surrounds all nerves outside the brain; it acts as a nerve insulator and helps in the transmission of nerve signals.

## Case history 2: Ms F

I developed MS about four years ago. It was odd to start with. I didn’t think I had anything serious, although you do worry about symptoms you don’t understand. It started when I had some problems with my sight. I couldn’t see as well as I used to be able to – it came on suddenly so I didn’t think it was age or anything normal. I think at the time I was also a bit more clumsy than I had been – nothing obvious, but I dropped things a bit more than before. Nothing really that you’d notice unless other things were happening as well. I went to my GP about my eyes and he sent me to see a neurologist. He tried to reassure me that there was nothing too badly wrong and that he wanted to check out a few symptoms. But I began to worry then ... you don’t get sent on to see the hospital doctors unless there is anything really wrong with you. He suggested that he thought it might be MS, which was why he was not sending me to an eye specialist.

I got to see the neurologist pretty quickly and she ran a few tests over a few weeks – testing my muscle strength, coordination, scans and so on ... sticking needles into me at various times. The upshot of this was that I was diagnosed as having MS. My consultant told me and my husband together, and allowed us to ask questions about things. We also got to speak to a specialist nurse who has helped us over the years. She was able to take the time to tell us more than the doctor about what to expect and what support we could have. Although I think it was nice to hear the diagnosis from the doctor.

I must admit that I found it really hard to deal with things at the beginning – you don’t know what to expect and perhaps you expect the worst. You hear all sorts of horror stories about people dying with MS and that. And no one can really reassure you that you won’t have problems ... Over the last few years, I’ve got to know my body and seen things getting worse. But it happens gradually and a lot of the time there are no changes. So that is reassuring – that things aren’t going to collapse too quickly and I won’t be left incontinent and unable to feed myself for a long time – hopefully not ever!

The worse thing is the tiredness and clumsiness. My eyes have actually got better, thank goodness. I use sticks to get around the house. Sometimes I can walk a little out of the house. Often I have to take the wheelchair. I just get exhausted too quickly, there isn’t a lot of point trying to walk, because I cannot go far ...

I hate having MS. I used to take part in sports, go out, be lively. Now I can’t do any of that. I’m tired ... down a lot of the time. I think the two often go together. My memory was never that good, but now it seems to be worse than ever. I can hold conversations, but keeping my concentration up for a long time is difficult. So, people find you difficult to deal with. I know my husband feels that way. He married a lively, sporty, slim woman ... now I’m lethargic, down, putting on weight because I eat and don’t exercise – even though they tell me not to, so I can keep mobile and not develop skin problems. I don’t go out very much because it’s such a hassle in my wheelchair ... cities were not designed for people in wheelchairs ... and people don’t like people in wheelchairs. You are ignored ... and just want to say, ‘Hey, I’m here. I have a brain you know ... ’ I know this sounds sorry for myself. And sometimes I feel more positive. But I find living with uncertainty difficult. Will I have a bad day today? Will I have a flare-up – have to go to hospital, take mega-steroids, come out worse than when I went in? I guess you have to live for the day ... but it can be difficult.

We examine the impact of MS on caregivers in Chapter 15 ☛ and some interventions designed to reduce the problems of living with the condition in Chapter 17 ☛.

The NICE guidelines for treatment of MS (NICE, 2019a) identify a number of medical treatments for each of the symptoms of MS, including plasticity, pain and so one. Notably, psychological treatments including mindfulness for mood disturbance and behavioural programmes to maintain movement are also key to its treatment. There is no 'overall' treatment of MS, although one approach involving a type of interferon has been proposed. Beta interferon appears to inhibit the action of gamma interferon and prevents the T cells attacking the myelin sheath. Unfortunately, interferons have to be regularly injected, and are responsible for the fever, muscle aches, fatigue and headache experienced during illnesses such as influenza. They are also very expensive, and NICE have not recommended the use of these drugs except in specific cases on the grounds of poor cost-effectiveness. There is increasing evidence that cannabis can be effective in reducing pain and muscle spasticity associated with MS. But the treatment has to counter the problems of its legal status. It is legally prescribed, for example, in the Netherlands, Canada, Australia and 36 states in the USA. Medicinal cannabis is legal in the UK, but access is limited to prescription by specialist clinicians.

# The digestive system

The digestive tract (see Figure 8.5) is the system of organs responsible for the ingestion of food, absorption of nutrients from that food, and finally the expulsion of waste products from the body. It comprises a number of connected organs, each with a different role:

- *Mouth*: here, food is masticated by chewing, causing the release of enzymes in the saliva and beginning the process of digestion.
- *Oesophagus*: this transports food from the mouth to the stomach, compressing it in the process.
- *Stomach*: here, food is churned and mixed with acid to decompose it chemically.
- *Small intestine*: this is responsible for mixing the bowel contents with chemicals to break it into its constituent parts and then absorbing them into the bloodstream for transportation to other organs. Chemicals involved in this process include **bile**, which is made by

**bile**

a digestive juice, made in the liver and stored in the gallbladder; involved in the digestion of fats in the small intestine.

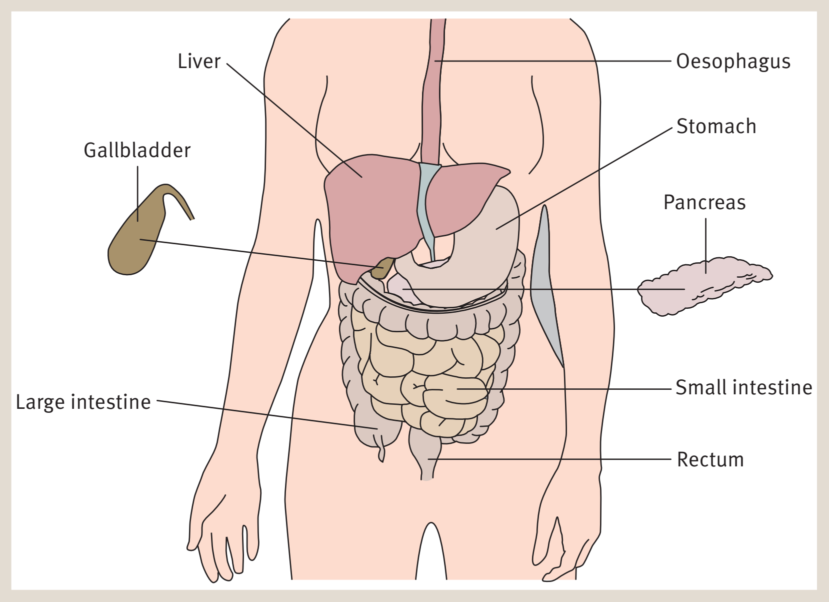


**Figure 8.5** The large and small intestine and related organs.

the liver and stored in the **gallbladder** and digests fats, and enzyme-rich juices released from the pancreas.

- *The large bowel* (colon): this is largely responsible for reabsorption of water from the bowel contents and expulsion of the unused bowel contents.

Movement between and along these various organs is controlled by a process known as peristalsis. This involves smooth muscle within the walls of the organs narrowing and the narrow sections moving slowly along the length of the organ in a series of waves, pushing the bowel contents forward with each wave.

## Controlling digestion

Each of these digestion processes is controlled by both hormone and nerve regulators. Hormones are produced and released by cells in the mucosa (lining) of the stomach and small intestine at key stages in the digestive process. Among other roles:

- Gastrin causes the stomach to produce its acid.
- Secretin causes the pancreas to produce a fluid that is rich in bicarbonate and enzymes to break down food into its constituent proteins, sugars and so on. The bicarbonate is alkaline and prevents the bowel wall from being damaged as the highly acidic stomach contents are released into the small intestine. Secretin also stimulates the liver to produce bile, the acid that aids fat digestion.
- Cholesystokinin triggers the gallbladder to discharge its bile into the small intestine.

Activity in the digestive system is also controlled by a complex local nervous system known as the enteric nervous system, in which:

- Sensory neurons receive information from receptors in the mucosa and muscle. Chemoreceptors monitor levels of acid, glucose and amino acids. Sensory receptors respond to stretch and tension within the wall of the gut.
- Motor neurons, whose key role is to control gastrointestinal motility (including peristalsis and stomach motility) and secretion, control the action of smooth muscle in the wall of the gut.

gallbladder

a structure on the underside of the liver on the right side of the abdomen, it stores the bile that is produced in the liver before it is secreted into the intestines; this helps the body to digest fats.

Key neurotransmitters involved in the activity of the enteric nervous system are noradrenalin and acetylcholine: the former provides an activating role, the second an inhibitory role. The enteric nervous system works independently of the central nervous system. However, the gut also has links to the central nervous system, providing sensory information (such as fullness) to the hypothalamus and allowing the gut to respond to the various excitatory or inhibitory processes of the autonomic nervous system. In general, sympathetic stimulation inhibits digestive activities, inhibiting gastrointestinal secretion and motor activity, and contracting gastrointestinal sphincters and blood vessels. The latter may be experienced as feelings of ‘butterflies in the stomach’ – and also some other, perhaps even more obvious, symptoms! Conversely, parasympathetic activity typically stimulates digestive activities.

## Disorders of the digestive system

### Gastric ulcer

Gastric ulcers are ulceration of the lining of the stomach (mucosa), which can result in a number of symptoms, the most common of which is abdominal discomfort or pain. This typically comes and goes for several days or weeks, occurs two to three hours after eating, is relieved by eating, and may be at its worst during the night – when the stomach is empty following a meal. Other symptoms include poor appetite, weight loss, bloating, nausea and vomiting. If the disease process is not treated, the ulcer may erode through the stomach wall, resulting in the potentially fatal outflow of its contents into the abdomen.

Until relatively recently, gastric ulcers were thought to be a consequence of stress, which was thought to increase acid secretion in the stomach. More recent evidence, however, has shown that a bacterium known as *Helicobacter pylori* is responsible for 70 per cent of cases of the disorder. *Helicobacter pylori* infection is thought to weaken the protective mucous coating of the stomach and duodenum and allow acid to reach the sensitive lining beneath. It may also increase the amount of stomach acid secreted. Both acid and bacteria irritate the stomach lining and cause the ulcer. Stress may, nevertheless, still be implicated in the development and maintenance of gastric ulcers as it may increase risk behaviours such as smoking or alcohol consumption, as well as adversely affecting the immune system's ability to influence levels of *H. pylori* in the gut.

Treatment involves suppressing acid secretion and, if appropriate, eradicating the *H. pylori* bacteria. Various types of drugs may be used to achieve this effect. Reductions in acid production can be achieved by histamine blockers (e.g., Cimetidine) and drugs known as hydrogen pump antagonists (e.g., Omeprazol). Drugs which eradicate *H. pylori* include antibiotics such as tetracycline or amoxicillin which are frequently given in combination with histamine blockers or hydrogen pump antagonists. Only rarely is surgery used in the treatment of gastric ulcers, and this usually when the ulcer has eroded through the stomach wall and has led to life-threatening haemorrhage.

## Inflammatory bowel disease

**Inflammatory bowel disease** (IBD) is a group of inflammatory conditions of the large and, in some cases, small intestine. The main forms of IBD are:

- Crohn's disease
- ulcerative colitis.

### Crohn's disease

Crohn's disease can involve any part of the gastrointestinal tract. It is an inflammatory condition characterised by episodes of severe symptoms followed by periods of remission. Its key symptoms are chronic, and occasionally severe, diarrhoea and disrupted digestion. Over time, the inflammation process can result in a thickening of the bowel wall, which may result in the diameter of the bowel becoming so constricted that food cannot pass through these damaged sections. These may require surgical excision. Unfortunately, as the disease tends to recur at these sites, the constriction may reoccur and require further surgery within a few years. For this reason, surgery is often considered the treatment of last resort. There is some evidence that the condition may have a genetic basis, although a diet high in sugar and fats, smoking and stress have also been implicated in its aetiology. The usual age of onset is between 15 and 30 years of age, with no difference in prevalence between men and women. Its symptoms include:

- abdominal pain;
- changes in bowel movements – faeces may vary between solid and watery;
- periods of mild fever, sometimes with blood in the stools, and pain in the lower right abdomen;
- loss of appetite;
- unintentional weight loss;
- boils and **fistulas**;
- general malaise.

At times of acute symptoms, individuals become severely dehydrated and are unable to digest food and absorb necessary nutrients, resulting in the need for significant medical care. At such times, a number of drugs designed to reduce inflammation and antibiotics may be necessary.

### Ulcerative colitis

**Ulcerative colitis** is similar to Crohn's disease, but usually affects the terminal part of the large intestine and rectum. It may develop into cancer after many years of the disease. For this reason, patients have regular check-ups for the beginning of cancer or even have preventive removal of segments of the bowel. This may result in the affected individual needing a **colostomy**. Its severity can be graded as:

- *Mild*: fewer than four stools daily, with or without blood. There may be mild abdominal pain or cramping.

inflammatory bowel disease

a group of inflammatory conditions of the large intestine and, in some cases, the small intestine; the main forms of IBD are **Crohn's disease** and **ulcerative colitis**.

Crohn's disease

autoimmune disease that can affect any part of the gastrointestinal tract but most commonly occurs in the ileum (the area where the small and large intestine meet).

fistulas

formation of small passages that connect the intestine with other organs or the skin.

ulcerative colitis

a chronic inflammatory disease of the large intestine, characterised by recurrent episodes of abdominal pain, fever and severe diarrhoea.

colostomy

a surgical procedure that creates an opening (stoma) in the abdomen for the drainage of stool from the large intestine (colon); it may be temporary or permanent.

- *Moderate*: more than four stools daily. Patients may be anaemic and have moderate abdominal pain and low grade fever.
- *Severe*: more than six bloody stools a day, and evidence of systemic disease such as fever, **tachycardia**, or anaemia.
- *Fulminant*: ten bowel movements daily, continuous bleeding, abdominal tenderness and distension. Patients will require blood transfusion and their colon may perforate, resulting in the gut content being released into the abdomen. Unless treated, fulminant disease will soon lead to death.

The goals of treatment with medication are to treat acute episodes and to maintain remission once achieved. Treatment is similar to that of Crohn's disease, and involves steroids to reduce inflammation and immunomodulators which suppress the body's immune processes that are contributing to the condition. Interestingly, risk of developing ulcerative colitis appears to be higher in non-smokers and in ex-smokers, and some patients may actually improve when treated with nicotine.

## Irritable bowel syndrome

**Irritable bowel syndrome** (IBS) is a condition of the bowel involving a period of at least three months abdominal discomfort or pain, with two or more of the following features:

- pain, relieved by defaecation;
- pain associated with a change in the frequency of bowel movements;
- change in the form of the stool (loose, watery, or pellet-like).

**tachycardia**

high heart rate – usually defined as greater than 100 beats per minute.

**irritable bowel syndrome**

a disorder of the lower intestinal tract; symptoms include pain combined with altered bowel habits resulting in diarrhoea, constipation or both; it has no obvious physiological abnormalities, so diagnosis is by the presence and pattern of symptoms.

Also central to a diagnosis of IBS is that these symptoms occur in the absence of any obvious physical pathology. Because of this lack of physical pathology, IBS was at one time considered to be the archetypal psychosomatic disorder. However, evidence of this link to stress is not as strong as was previously thought, and other factors have now been linked with IBS. These include food hypersensitivities and the presence of bacteria such as Blastocystis hominis and *Helicobacter pylori* (see Singh et al., 2003). Spence and Moss-Morris (2007) argued that the initial trigger to IBS may be an infection (an episode of gastroenteritis), with the condition maintained in the longer term by high levels of anxiety and/or stress. While IBS may be unpleasant, and some people may be restricted by the pain they experience or the fear of not being able to get to a toilet in time if they were to have diarrhoea, it is not a life-threatening condition nor as debilitating as the previously described conditions.

Following NICE guidelines (NICE, 2017b), medical treatment involves the use of smooth muscle relaxants to reduce gut motility, adding or reducing fibre to the diet (depending on the level of fibre already in the diet), drugs which 'bulk' up stools to reduce diarrhoea and, on occasion, anxiolytic or anti-depressant drugs. Psychological treatment is recommended if patients have not responded to medical treatment over a period of one year. We examine the rationale and types of psychological treatments for IBS in more detail in Chapter 17 ☛, and the role of stress in the development of bowel disorders in Chapter 11 ☛.

## Colorectal cancer

Colorectal cancer is the third most common cancer in men and women. Risk for the condition is increased by both biological and behavioural factors, including genetic factors, pre-existing inflammatory conditions including ulcerative colitis, and a diet high in fat and low in fibre. Symptoms of the disorder are often unnoticed because they are relatively mild, and include bleeding, constipation or diarrhoea, and unformed stool. One early symptom may be a general tiredness and shortness of breath as a consequence of anaemia caused by long-term, but unnoticed, bleeding within the gut. For this reason, the cancer may be quite advanced before people seek medical help. It is nevertheless generally treatable with a combination of surgery to remove the cancer followed by chemotherapy. Radiotherapy is rarely used except in cases of rectal cancer. As with many cancers, the condition can be described in terms of its stages, with the higher stage being more difficult to treat and having a poorer **prognosis**:

- *Stage 1*: the cancer is limited to the inside of the bowel.
- *Stage 2*: the cancer penetrates through the wall of the bowel to the outside layers.
- *Stage 3*: the cancer involves the lymph glands in the abdomen.
- *Stage 4*: the cancer has metastasised to other organs.

# The cardiovascular system

The main function of the cardiovascular system is to transport nutrients, immune cells and oxygen to the body's organs and to remove waste products from them. It also moves hormones from their point of production within the body to their site of action. The transport medium used in this process is the blood; the pumping

**prognosis**
the predicted outcome of a disease.

## IN THE SPOTLIGHT

### Cancer

Hundreds of genes play a role in the growth and division of cells. Three classes of gene control this process and may contribute to the uncontrolled proliferation of cells, which is cancer:

1. *Oncogenes* control the sequence of events by which a cell enlarges, replicates its DNA, divides and passes a complete set of genes to each daughter cell. When mutated, they can drive excessive proliferation by producing too much, or an overactive form, of a growth-stimulating protein.
2. *Tumour suppressor genes* inhibit cell growth. Loss or inactivation of this gene may produce inappropriate growth by losing this inhibitory control.
3. Checkpoint genes monitor and repair DNA, which is often damaged prior to reproduction and needs to be repaired before cell division. Without these checking mechanisms, a damaged gene will become replicated as a permanent mutation. One of the most notable checkpoint proteins is known as p. 53, which prevents replication of damaged DNA in the normal cell and promotes **cell suicide** in cells with abnormal DNA. Faulty p. 53 allows cells carrying damaged DNA to replicate and survive and has been found to be defective in most human cancers.

Other factors are also important in tumour development. Growing tumours are dependent on a good blood supply. To promote this, local tissues may be transformed into blood vessel cells, allowing the tumour to establish its own blood supply. Some modern treatments of cancer attack this blood supply as well as the tumour mass itself. Tumours also acquire the ability to migrate and invade other tissues, forming tumour masses at different sites in the body. This process is known as metastasis – and in some cases these secondary tumours may be more deadly than the original tumour.

**cell suicide**
a form of cell death in which a controlled sequence of events (or programme) leads to the elimination of cells without releasing harmful substances into the surrounding area.

system that pushes the blood around the body involves the heart and various types of blood vessel:

- *Arteries*: transport blood away from the heart. These vessels have a muscular sheath that allows them to contract or expand slightly. This activity is controlled by the autonomic nervous system.
- *Arterioles*: these are small arteries, linking the large arteries to the organs of the body.
- *Veins*: these transport blood back to the heart once the oxygen and nutrients have been absorbed from it and replaced by carbon dioxide, and a variety of waste products. They are thinner than arteries, and because they are so far from the heart have much lower pressures than the arteries. Blood is pushed through them partly by the pressure of the pulse of blood from the heart, partly through the action of the moving muscles. As large muscle groups contract during everyday activities, they push blood through the veins. To prevent back flow of blood they have a series of valves, which allow the blood to flow in only one direction. When the muscles are inactive, blood may no longer flow freely in the veins and may even stagnate and begin to clot – a deep vein thrombosis that may occur after long-haul flights or other periods of inactivity in some susceptible individuals.

## The heart

The heart has two separate pumps operating in parallel. The right side of the heart is involved in the transportation of blood to the lungs; the left side pumps blood to the rest of the body (Figure 8.6). Each side of the heart has two chambers (Figure 8.7), known as atria and ventricles. The right atrium takes deoxygenated blood from veins known as the superior and inferior vena cava and pumps it into the right ventricle. Blood is then pumped into the pulmonary artery, taking it to the lungs, where it picks up oxygen in its **haemoglobin** cells. Oxygen-laden blood

**haemoglobin**
the main substance of the red blood cell; when oxygenated in the lungs, it is converted to oxyhaemoglobin, thus allowing the red blood cells to carry oxygen from the air in our lungs to all parts of the body.

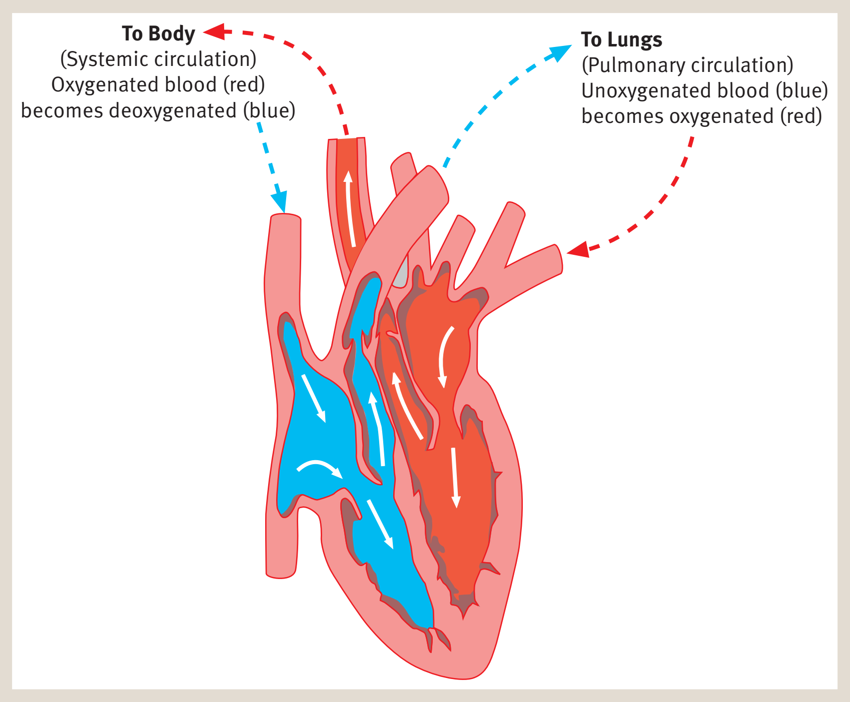


**Figure 8.6** The flow of blood through the heart

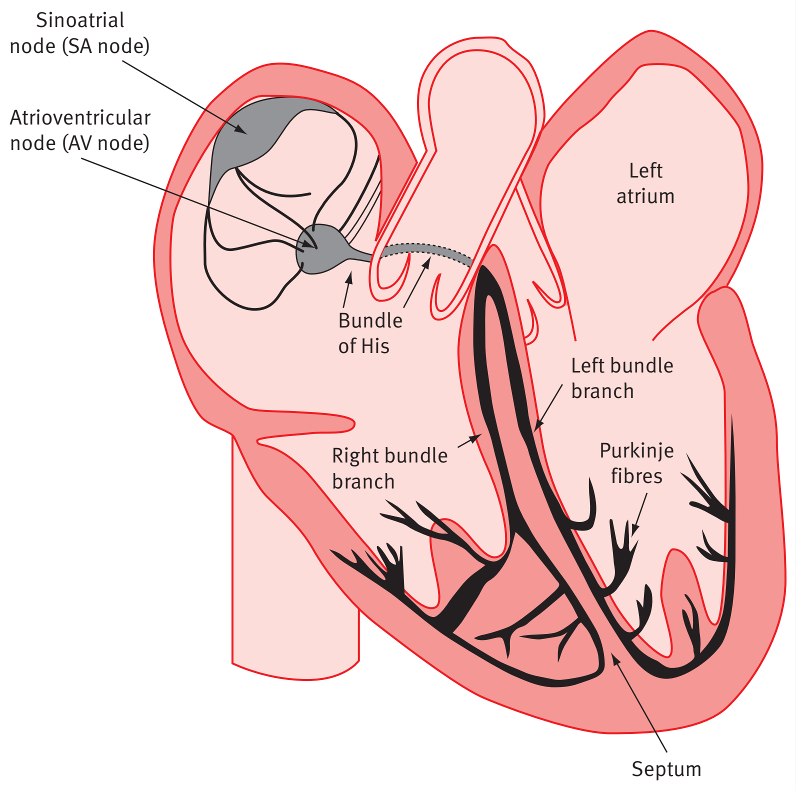


**Figure 8.7** Electrical conduction and control of the heart rhythm

then returns to the heart, entering through the left atrium. It is then pumped into the left ventricle, and then into the main artery, known as the **aorta**, which carries blood to the rest of the body.

The rhythm of the heart is controlled by an electrical system. It is initiated by an electrical impulse generated in a region of the right atrium called the sinoatrial node. This impulse causes the muscles of both atria to contract. As the wave of electricity progresses through the heart muscle and nerves, it reaches an area at the junction of the atria and ventricles known as the atrio-ventricular node. This second node then fires a further electrical discharge along a system of nerves including the Bundle of His and Purkinje fibres (see Figure 8.7), triggering the muscles of both ventricles to contract, completing the cycle. Although the sinoatrial node has an intrinsic rhythm, its activity is largely influenced by the autonomic nervous system.

An electrocardiogram (ECG) is used to measure the activity of the heart. Electrodes are placed over the heart and can detect each of the nodes firing and recharging. Figure 8.8 shows an ECG of a normal heart, indicating the electrical activity at each stage of the heart's cycle.

- The P wave indicates the electrical activity of the atria firing – the time needed for an electrical impulse from the sinoatrial node to spread throughout the atrial musculature.
- The QRS complex represents the electrical activity of the ventricles compressing.
- The T wave represents the repolarisation of the ventricles.

When the heart stops beating or its electrical rhythm is completely irregular and no blood is being pushed around

aorta

the main trunk of the systemic arteries, carrying blood from the left side of the heart to the arteries of all limbs and organs except the lungs.

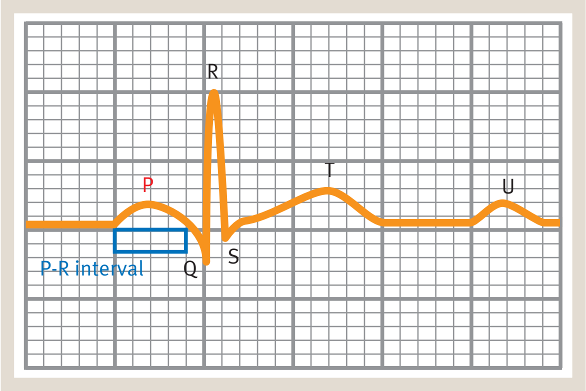


**Figure 8.8** An electrocardiograph of the electrical activity of the heart (see text for explanation)

the body, doctors may use a **defibrillator** to stimulate a normal (sinusoidal) rhythm.

## Blood

The body usually contains about five litres of blood. Its constituents include a fluid known as plasma and a variety of cells. As well as the various **exogenous** cells carried in the blood (nutrients, oxygen, etc.), it produces its own cells. These are manufactured by **stem cells** in the bone marrow. Three different types of cell are produced:

1. **Erythrocytes** (or red blood cells) transport oxygen around the body. In them, oxygen combines with haemoglobin in the lungs and is transported to cells in need of oxygen, where it is released, allowing cell respiration.
2. Phagocytes and lymphocytes (or white blood cells; see above) include the immune system's B cells and T cells described earlier in the chapter.
3. **Platelets** are cells that respond to damage to the circulatory system. They aggregate (form a clot) around the site of any damage and prevent loss of blood from the system. They are also involved in repair to damage within the arteries themselves and contribute to the development of atheroma. We consider this process later in the chapter.

### Blood pressure

Blood pressure has two components:

1. the degree of pressure imposed on the blood as a result of its constriction within the arteries and veins – known as the diastolic blood pressure (DBP);
2. an additional pressure as the wave of blood pushed out from the heart flows through the system (our pulse) – known as the systolic blood pressure (SBP).

This pressure is measured in millimetres of mercury (mmHg), representing the height of a tube of mercury in millilitres that the pressure can push up (using a now old-fashioned sphygmomanometer). Healthy levels of blood pressure are an SBP below 130–140 mmHg and a DBP below 90 mmHg (written as 130/90 mmHg: see also the discussion of hypertension later in the chapter).

A number of physiological processes are involved in controlling blood pressure. Those of particular interest to psychologists involve the autonomic nervous system. The brainstem receives continuous information from pressure-sensitive nerve endings called **baroreceptors**

defibrillator

a machine that uses an electric current to stop any irregular and dangerous activity of the heart's muscles. It can be used when the heart has stopped (cardiac arrest) or when it is beating in a highly irregular (and ineffective) manner.

exogenous

relating to things outside the body.

stem cell

a 'generic' cell that can make exact copies of itself indefinitely; in addition, such cells have the ability to produce specialised cells for various tissues in the body, including blood, heart muscle, brain and liver tissue; found in the bone marrow.

erythrocyte

a mature blood cell that contains haemoglobin to carry oxygen to the bodily tissues.

platelets

tiny bits of protoplasm found in the blood that are essential for blood clotting; these cells bind together to form a clot and prevent bleeding at the site of injury.

baroreceptors

sensory nerve endings that are stimulated by changes in pressure; located in the walls of blood vessels such as the carotid sinus.

situated in the **carotid arteries** and aorta. This information is relayed to a centre in the brainstem known as the vasomotor centre, and then on to the hypothalamus. Reductions in blood pressure or physical demands such as exercise that require increased blood pressure causes activation of the sympathetic nervous system. Sympathetic activation results in an increase in the strength and frequency of heart contractions (via the activity of the sinoatrial and atrioventricular nodes) and a contraction of the smooth muscle in the arteries. Together, these actions increase in blood pressure, and allow sustained flow of blood to organs such as the muscles at times of high activity. Parasympathetic activity results in an opposing reaction.

## Diseases of the cardiovascular system

### Hypertension

Hypertension is a condition in which resting blood pressure is significantly above normal levels (see Table 8.2).

Two broad causes of hypertension have been identified:

1. *Secondary hypertension*: here, hypertension is the result of a disease process usually involving the kidneys, adrenal glands or aorta. This type of hypertension accounts for about 5 per cent of cases.
2. *Essential* (*primary*) *hypertension*: in the majority of cases, there is no known disease process that causes the problem. It seems to be the ‘normal’ consequence of a number of risk factors, such as obesity, lack of exercise and a high salt intake. It is a progressive condition, and people with the condition usually experience a gradual rise in blood pressure over a period of years, with no obvious symptoms.

Hypertension may be present and remain unnoticed for many years, or even decades. It is usually considered to be a syndrome with few if any symptoms, and many cases of hypertension are detected during routine screening (see Chapter 6 ☛). If high blood pressure has no symptoms, why bother treating it? Because of its systemic effects on a range of bodily organs. High blood pressure increases the risk of a heart attack (**myocardial infarction (MI)** – see below), stroke, kidney failure, eye damage and **heart failure**. It also contributes to the development of atheroma. It is usually treated with antihypertensive drugs with a variety of actions, including **ACE inhibitors**, **diuretics** and **beta-blockers**, all of which have been proven effective. Some have argued that medical treatment of relatively low levels of high blood pressure – stage 1 hypertension (140–159 mmHg) – may actually be of little benefit and bring significant unwanted

**Table 8.2** Typical blood pressure readings in normal and hypertensive individuals

| | Diastolic (mmHg) | Systolic (mmHg) |
|---|---|---|
| Normal | ≤90 | ≤140 |
| Mild hypertension | 90–99 | 140–159 |
| Hypertension | 100 | ≥160 |

**carotid artery**

the main artery that takes blood from the heart via the neck to the brain.

**myocardial infaction**

(aka, heart attack): death of heart muscle due to lack of oxygen; this results from an obstruction in blood supply due to a clot blocking one or more arteries supplying the heart with oxygen.

**heart failure**

a state in which the heart muscle is damaged or weakened and is unable to generate a cardiac output sufficient to meet the demands of the body.

**ACE inhibitors**

angiotensin II causes the muscles surrounding blood vessels to contract and thereby narrows the blood vessels. Angiotensin Converting Enzyme (ACE) inhibitors decrease the production of angiotensin II, allowing blood vessels to dilate, and reduce blood pressure.

**diuretics**

elevate the rate of bodily urine excretion, reducing the amount of fluid within the cardiovascular system, and reducing pressure within it.

**beta-blockers**

block the action of adrenaline and noradrenaline on $\beta$ adrenergic receptors, which mediate the ‘fight or flight’ response, within the heart and in muscles surrounding the arteries. In doing so, they reduce increases in blood pressure associated with sympathetic activation.

side-effects. However, new treatments now suggest that for all men and women over the age of 45 years, treating this level of hypertension is likely to be of benefit. Treating women under the age of 44 with stage 1 hypertension is likely to be less beneficial (NICE, 2019b).

## Coronary heart disease

Like hypertension, coronary heart disease (CHD; or ischaemic heart disease (IHD) as it may also be termed) may develop over many years before becoming evident. Indeed, people may have quite significant heart disease and never be aware of their condition. The long-term, and silent, element of CHD is the development of atheroma in the blood vessels. This may eventually cause more obvious manifestations of CHD, including an MI and angina (see below).

### Atherosclerosis

Atherosclerosis is a disease in which atheroma builds up on lining of the arteries. The main constituent of atheroma is cholesterol. This is a waxy substance that is present in blood plasma and in all the body's cells. Without it, cells could not maintain the integrity of their walls, and we would become seriously ill or die. Too much cholesterol, on the other hand, may be harmful. To get to the cell walls in order to repair and maintain them, cholesterol must be transported through the body via the bloodstream attached to groups of proteins called lipoproteins. **Low-density lipoproteins** (LDLs) transport cholesterol to the various tissues and body cells, where it is separated from the lipoprotein and is used by the cell. It can also be absorbed into atheroma on the inner surface of the blood vessels. **High-density lipoproteins** (HDLs) transport excess or unused cholesterol from the tissues back to the liver, where it is broken down to bile acids and then excreted. LDLs are therefore characterised as 'harmful' cholesterol; HDLs are considered to be health-protective. Although some cholesterol is absorbed from our food through the gut, about 80 per cent of cholesterol in our bodies is produced by the liver. The development of atherosclerosis involves a series of stages:

low-density lipoprotein (LDL)

the main function of LDL seems to be to carry cholesterol to various tissues throughout the body; LDL is sometimes referred to as 'bad' cholesterol because elevated levels of LDL correlate most directly with coronary heart disease.

high-density lipoprotein (HDL)

lipoproteins are fat protein complexes in the blood that transport cholesterol, triglycerides and other lipids to various tissues; the main function of HDL appears to be to carry excess cholesterol to the liver for 're-packaging' or excretion in the bile; higher levels of HDL seem to be protective against CHD, so HDL is sometimes referred to as 'good' cholesterol.

- *Early processes*: atheroma usually occurs at sites of disturbed blood flow, such as bifurcations of the arteries. It forms as part of the repair process to damage of the artery wall caused by the disturbed blood flow in these areas. In this process, inflammatory monocytes, which are precursors to macrophages (see the section on the immune system earlier in the chapter), absorb LDL cholesterol from the circulating blood to become what are known as foam cells. These form a coat over the lining of the damaged artery. As the foam cells die, they lose their contents of LDL, resulting in pools of cholesterol forming between the foam cells and the artery wall. The presence of foam cells may trigger the growth of smooth muscle cells from the artery wall to cover them. In this way, the walls of the artery become lined with lipids, foam cells and finally a wall of smooth muscle. This repeated process results in a gradual reduction of the diameter of the artery.
- *Acute events*: at times, more acute events may occur, and clots of cholesterol and foam cells may be pulled out of the artery wall. This may result in a clot blocking an artery in a key organ such as the heart, resulting in an MI (see below).

The distribution of atheroma within the circulatory system is not uniform throughout the body. It is most developed around the junctions of arteries because disturbances in blood flow at such points can facilitate these processes, but the heart arteries are some of the blood vessels most likely to be affected. The ideal levels for the various cholesterol measurements are:

- Total cholesterol less than or equal to 5mmol/L
- LDL cholesterol less than or equal to 3mmol/L
- HDL cholesterol greater than or equal to 1mmol/L
- LDL:HDL ratio less than or equal to 4

Unfortunately, many people do not achieve these optimal levels. The 2017 Health Survey for England (NHS Digital, 2019), for example noted the percentage of UK adults (including those taking lipid lowering medication) with total cholesterol greater than or equal to 5mmol/L were as follows:

- 35–44: 63 per cent of men and 40 per cent of women
- 45–54: 63 per cent of men and 69 per cent of women
- 55–64: 58 per cent of men and 76 per cent of women.

NICE guidelines (NICE, 2016) suggest high levels of cholesterol may be treated with drugs known as statins if dietary changes are insufficient to lower cholesterol to safe levels. They work by blocking production of an enzyme (HMG-CoA reductase) the liver needs to make cholesterol. They may also help reabsorb cholesterol that has accumulated in atheroma on the artery walls. Although there are apparently clear cut-offs for treatment with statins, decisions about whether to treat raised cholesterol may be based on a wider measure of overall risk for CHD, and patient preferences. The potential for negative side-effects of statins and the, at best, modest reductions in risk for CHD among people with mildly raised cholesterol (Chou et al., 2016), for example, may mitigate against treating people at this level of risk, particularly if they have no other risk factors.

### Myocardial infarction

As we noted in the last section, an important end point of CHD is when a clot is torn off an artery wall and enters the circulating blood. This may prove a harmless event, with no health implications for the individual. However, if the circulating clot has a greater diameter than the blood vessels it is passing through, it will inevitably block the blood vessel and prevent the flow of blood beyond this blockage. This occlusion may result in significant health problems if it occurs in the arteries supplying oxygen and nutrients to the heart. Unless rapidly treated, the cells of the heart muscle beyond the occlusion no longer receive their nutrients and oxygen and die – a myocardial infarction (MI). The severity of the MI is determined by how large a blood vessel is affected (larger is worse) and which parts of the heart are damaged.

The classic symptoms of an MI include what is often described as 'crushing chest pain'. The affected individual may feel like their chest is trapped in a vice. Other symptoms include shortness of breath, coughing, pain radiating down the left arm, dizziness and/or collapse, nausea or vomiting, and sweating. However, an MI may also be much less dramatic. Indeed, many people delay seeking help for an MI as their symptoms are vague, may be confused with heartburn or indigestion, and the affected individual hopes they will go away without treatment. Perhaps the strangest symptom that can rarely be indicative of an MI is toothache – although we would not recommend you visit your local hospital complaining of a heart attack should you be unfortunate enough to develop this problem!

Depending on the site of the infarction within the heart, around 2.5 to 10 per cent of people will die of their MI immediately or in the month or so following the event (e.g. Rosamond et al., 2012). The majority go on to make a good recovery. This may be aided by treatment with drugs known as '**clot busters**' (or more technically, thrombolytics). These drugs dissolve the clot causing the blocked artery and, if given within an hour or so of the infarction, can prevent permanent muscle damage. Longer-term treatment now frequently involves a procedure known as an angioplasty (or its longer formal name, Percutaneous Transluminal Coronary Angioplasty: PTCA) in which a long narrow catheter is inserted into the femoral artery (near the groin) and, guided by X-rays, is pushed along the arteries until it reaches the coronary arteries. After reaching the site of the MI, a small balloon is inflated which pushes against the occluded artery wall, increasing the diameter of the artery and allowing normal blood flow through it. A small wire mesh tube (known as a stent) is then frequently left in position at the site to maintain the patency of the artery. A number of drug treatments may be required depending on individual pathology, but may include:

- Antiplatelet drugs, such as aspirin and clopidogrel, can be used to prevent new clots forming and existing clots growing.
- Beta-blockers or Angiotensin-converting enzyme (ACE) inhibitors lower blood pressure and relax heart muscle.
- Statins may be used to reduce cholesterol levels if appropriate.

**clot busters**

drugs which dissolve clots associated with myocardial infarction and can prevent damage to the heart following such an event. Are best used within one hour of the infarction.

Long-term contributors to CHD, including high cholesterol or blood pressure may also be treated through appropriate lifestyle changes (see Chapters 6, 7 and 17 ☛).

### Angina

The key symptom of **angina** is similar to that of an MI. It is a central chest pain that may radiate to the left shoulder, jaw, arm or other areas of the chest. Some patients may confuse arm or shoulder pain with arthritis or indigestion pain. Unlike an MI, however, it is a temporary condition which occurs when the heart muscle needs more oxygen than can be provided by the heart arteries and stops once these demands are reduced. It is frequently precipitated by exertion or stress, and may result from two underlying causes:

1. atheromatous lesions of the coronary arteries reduce their diameter and limit the blood flow through them;
2. **vasospasm** of the coronary arteries results in a temporary reduction in their diameter;
3. a combination of both.

Classic angina (or angina pectoris) is associated with high levels of atheroma in the coronary arteries which limits the amount of blood they can carry to the heart muscle. Physical exertion, emotional stress and exposure to cold are among the triggers for this type of angina. In a second type of angina known as unstable angina, people with the condition experience angina symptoms after relatively little effort (such as just taking a few steps) or even when they are resting. It is usually the result of a severe narrowing in a coronary artery, which may lead to an MI if it is not treated. As with an MI, treatment involves interventions to reduce the immediate symptoms of angina and to prevent the underlying disease progress. Symptomatic relief can be achieved through the use of GlycerylTrinitrate (GTN: otherwise known as nitroglycerin!). This comes as a spray (sprayed into the mouth) or tablets (placed under the tongue) to take when an angina episode starts, and results in an immediate widening of the arteries and relief from symptoms. If the level of disease warrants it, patients with angina may also be given PTCA, or a **coronary artery bypass graft** (CABG), in which blood vessels are taken from the legs or the chest and used to bypass the diseased artery. Treatment of underlying conditions may involve the use of statins or hypertensive medication. In Chapter 17 ☛, we describe the case of Mr Jones, whose angina was so severe that on two occasions he believed he was having an MI and went to the emergency department of the local hospital. We also show how we helped him adjust better to his condition.

**angina**

severe pain in the chest associated with a temporary insufficient supply of blood to the heart.

**vasospasm**

a situation in which the muscles of artery walls in the heart contract and relax rapidly, resulting in a reduction of the flow of blood through the artery.

**coronary artery bypass graft**

surgical procedure in which veins or arteries from elsewhere in the patient's body are grafted from the aorta to the coronary arteries, bypassing blockages caused by atheroma in the cardiac arteries and improving the blood supply to the heart muscle.

## The respiratory system

The respiratory system delivers oxygen to and removes carbon dioxide from the blood. The exchange of oxygen and carbon dioxide occurs in the lungs. The system comprises:

- the *upper respiratory tract*, including the nose, mouth, larynx and trachea;
- the *lower respiratory tract*, including the lungs, bronchi, bronchioles and alveoli. Each lung is divided into upper and lower lobes – the upper lobe of the right lung contains a third subdivision known as the right middle lobe.

The bronchi carry air from the mouth to the lungs. As they enter the lungs, they divide into smaller bronchi, then into smaller tubes called bronchioles (see Figure 8.9). The bronchioles contain minute hairs called cilia, which beat rhythmically to sweep debris out of the lungs towards the pharynx for expulsion and thus form part of the mechanical element of the immune system – see earlier in the chapter. Bronchioles end in air sacs called alveoli – small, thin-walled 'balloons', which are surrounded by tiny blood capillaries. As we breathe in,

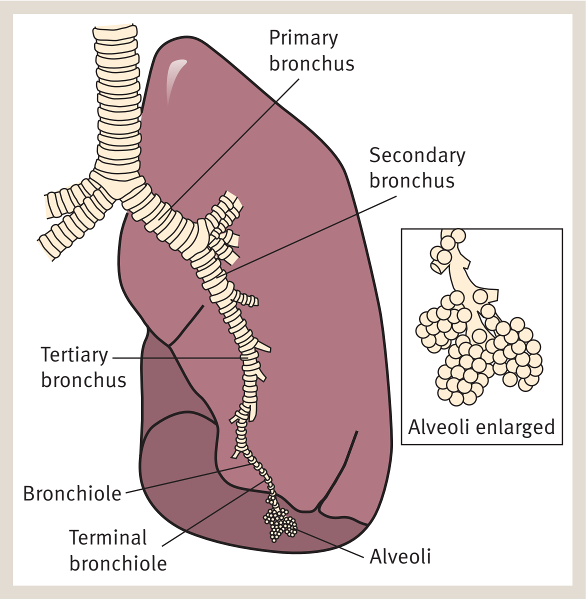


**Figure 8.9** Diagram of the lungs, showing the bronchi, bronchioles and alveoliAs we breathe out, carbon dioxide concentration in the blood is greater than that in the alveoli, so it passes from the blood into the alveoli and is then exhaled.

the concentration of oxygen is greater in the alveoli than in the haemoglobin in the blood travelling through the capillaries. As a result, oxygen diffuses across the alveolar walls into the haemoglobin.

Respiration is the act of breathing:

- *Inspiration*: two sets of muscles are involved in inhalation. The main muscle involved is the diaphragm. This is a sheet of muscle that divides the abdomen and is found immediately below the lungs. Contraction of this muscle pulls the lungs down and sucks air into them. The second set of muscles is known as the intercostal muscles. These are found between the ribs and can expand the chest – again pulling air into the lungs.
- *Expiration*: relaxation of the diaphragm and intercostal muscles allows the lungs to contract, decreases lung volume, and pushes air out of them. The air then passively flows out.

The rate of breathing is controlled by respiratory centres in the brainstem. These respond to:

- the concentration of carbon dioxide in the blood (high carbon dioxide concentrations initiate deeper, more rapid breathing);
- air pressure in lung tissue. Expansion of the lungs stimulates nerve receptors to signal the brain to 'turn off' inspiration. When the lungs collapse, the receptors give the 'turn on' signal, known as the Hering–Breuer inspiratory reflex.

Other automatic regulators include increases in blood pressure, which slows down respiration; a fall in blood acidity, which stimulates respiration; and a sudden drop in blood pressure, which increases the rate and depth of respiration.

## Diseases of the respiratory system

### Chronic obstructive airways disease

Chronic obstructive pulmonary disease (COPD) is a group of lung diseases characterised by limited airflow through the airways resulting from damage to the alveoli. Its most common manifestations are **emphysema** and **chronic bronchitis.**

### Emphysema

Emphysema results from the destruction of the alveoli, resulting in reduced lung elasticity and reductions in the surface area on which the exchange of oxygen and carbon dioxide can occur. People with the condition experience

**emphysema**

a late effect of chronic infection or irritation of the bronchial tubes; when the bronchi become irritated, some of the airways may become obstructed or the walls of the tiny air sacs may tear, trapping air in the lung beyond them – as a result, the lungs may become enlarged, at the same time becoming less efficient in exchanging oxygen for carbon dioxide.

**chronic bronchitis**

an inflammation of the bronchi, the main air passages in the lungs, which persists for a long period or repeatedly recurs; characterised by excessive bronchial mucus and a cough that produces sputum for three months or more in at least two consecutive years.

chronic shortness of breath, an unproductive cough (which produces no phlegm), and a marked reduction in exercise capacity. The condition typically results from exposing the alveoli to irritants, whether as a result of direct or passive smoking or living or working in a polluted environment. About 15 per cent of long-term smokers will develop COPD (Mannino, 2003). More rarely, an enzyme deficiency called alpha-1 anti-trypsin deficiency can cause emphysema in non-smokers. What is it like to live with emphysema? Well, here is a quote from someone (Gary Bain) with the condition taken from a self-help website (http://www.emphysema.net/my.asp).

> Sit down somewhere and relax a little and when you feel comfortable, take your right or left hand and with your thumb and forefinger, hold your nose shut. While holding your nose shut, cover your mouth tightly with the rest of your hand so you can just barely breathe through your fingers. Now, walk for about 40 steps and turn around and come back while still breathing through your hand. Now, do you see how hard it is to breathe? Especially when you try to walk around? That is what emphysema is ...

Treatment of emphysema involves a number of approaches. Most patients with the emphysema utilise bronchodilators that relax bronchial smooth muscle, dilate airways, and decrease airflow resistance. These drugs provide symptomatic relief, but do not stop disease progression. Some drugs (Short acting Beta-2 agonists; SABA) relieve acute symptoms of shortness of breath, while others (long-acting Beta agonists, LABA) may be used more regularly as a preventive treatment. A second, long acting, group of medications with a different mechanism of bronchodilation are known as long-acting muscarinic antagonists (LAMA). Some individuals with severe symptoms may need continuous oxygen therapy. Finally, as people with emphysema are prone to lung infections, they may require treatment with antibiotics.

## Chronic bronchitis

Chronic bronchitis results from inflammation and a consequent narrowing of the airways. Bronchitis is considered to be chronic when it persists for three months or more for at least two consecutive years. People with the condition experience shortness of breath and have excessive mucus within the bronchial tree and a 'wet' cough. They may also experience wheezing and fatigue. As with emphysema, it is caused predominantly by smoking and second-hand smoke. Allergies, outdoor and indoor air pollution, and infection may exacerbate the condition. Treatment involves the use of bronchodilators, and for some people, oxygen therapy (as in emphysema). Corticosteroids may also be used at times of acute severe episodes of breathing difficulty when other treatments are ineffective.

### Self-help for people with COPD

Unfortunately, the way many people cope with their COPD may inadvertently add to their problems. Understandably, people who become out of breath when they exercise stop doing so. It makes sense: breathlessness is both unpleasant and frightening. Unfortunately, this avoidance results in a decrease in lung function and a worsening of symptoms. As patients' contribution to their lung health has become more evident, a number of programmes have now been developed and implemented to teach people how best to cope with COPD. Often referred to as pulmonary rehabilitation (e.g. see British Lung Foundation, 2020), these provide advice on 'lung health' and coping with breathlessness, and a gentle physical exercise programme designed to increase fitness and lung capacity.

## Lung cancer

Lung cancer is the second most common cancer affecting both sexes. Its symptoms include a dry non-productive cough, shortness of breath, coughing up sputum with signs of blood in it, an ache or pain when breathing, loss of appetite, fatigue and losing weight. The main cause of lung cancer is smoking, and as women have taken up smoking following the Second World War, rates of lung cancer among this group have risen, while those among men have fallen (https://www.cancerresearchuk.org/). Other risk factors involve exposure to carcinogens, including asbestos and radon, and scarring from tuberculosis. There is some evidence of a genetic risk also.

Two different types of lung cancer have been identified:

1. *Small cell cancer*: the main treatment is radiotherapy or chemotherapy. The overall survival rate depends on the stage of the disease. For limited-stage small cell cancer, cure rates may be as high as 25 per cent, while cure rates for extensive-stage disease are less than 5 per cent.

2. *Non-small cell cancer* (between 70 and 80 per cent of cases): the main treatment for this type of cancer involves removal of the cancer through surgery. Where the tumour is small and has not spread, up to 50 per cent of people with the condition may survive. The prognosis is worse the larger the tumour. Where the tumour has spread and lymph nodes are involved, the disease is almost never cured, and the goals of therapy are to extend life and improve quality of life (Beadsmoore and Screaton, 2003).

We examine how people respond to having lung cancer in Chapter 9 ☛, and some interventions designed to help people with lung diseases in Chapter 17 ☛.

### Treatment for lung cancer

The treatment for lung cancer varies according to the degree of involvement of the lungs and the level of disease progression. For non-small cell cancer in one lung treatment will typically involve surgery to remove the cancerous cells followed by a course of chemotherapy. For more progressed cases, treatment may involve a combination of radio- and chemotherapy. Small-cell lung cancer is usually treated with chemotherapy, alone or in combination with radiotherapy. This can help to prolong life and relieve symptoms. Surgery is usually of little benefit because the cancer has often metastasized to areas of the body by the time of diagnosis.

## COVID-19

At the time of writing, the world was in crisis due to the number and severity of acute infections with a virus known as severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) or more familiarly COVID-19. The global epidemic affected over 8 million people and resulted in 400,000 deaths. Originating in Wuhan in China, the World Health Organization labelled the infections as a public health emergency on 30 January 2020, and a global pandemic on 11 March 2020. The virus is transmitted through respiratory droplets and aerosols from person to person. Once in the body, it binds to host cells, particularly those within the respiratory system, where it replicates and spreads through adjacent cells and is expired and contributes to further transmission of the virus through respiratory droplets. The infection can be considered to occur in stages (Parasher, 2020):

- *Asymptomatic phase*: this is in the first one- or two-days following infection and involves of initial infection and propagation in the cells of the airways in the nose. At this time, there are minimal symptoms, but the condition is highly infectious.
- *Invasion and infection of the upper respiratory tract*: at this time, the virus migrates from the nose to the upper respiratory tract. The individual becomes symptomatic, with fever, malaise and dry cough. A strong immune response is evoked, and most people do not progress beyond this stage.
- *Progression to Acute Respiratory Distress Syndrome (ARDS)*: around 20 per cent of infected individuals progress to experience severe symptoms. The virus affects the lungs. The immune system's response to this infection can be extremely powerful, and a range of cytokines including inflammatory interleukins can be triggered resulting in a so-called 'cytokine storm' triggering CD4+ and CD8 cytotoxic T cells. (see earlier in the chapter) These fight the virus, but also cause massive inflammation and damage to the lung tissue that results in short-term acute breathing problems, ARDS, as well as potentially longer term more chronic problems.

COVID-19 has also been found to increase risk for a range of health challenges including life-threatening thrombosis, damage to heart muscle, and even neurological damage similar to that found in MS and chronic fatigue. These may present acute problems during the third stage of infection and are responsible for many deaths at this stage. They may also be present during so-called 'long covid'; symptoms that last more than 12 weeks. These are likely to include shortness of breath, chest pain, heart palpitations, tachycardia, headaches, muscle and joint pain, fatigue and 'brain fog' (https://www.nice.org.uk/covid-19). So problematic are these symptoms, the UK government is establishing assessment and care pathways to ensure people with them access appropriate treatment (NHS, 2020).

Less heralded, but likely to be long-standing are the psychological consequences of having or caring for people with COVID-19. There is consistent evidence that people who have been ventilated in intensive care units are at high risk for post-traumatic stress disorder. Garrouste-Orgeas et al. (2019) found that around one-third of typical patients treated in intensive care and who were ventilated experienced significant PTSD symptoms three months post-discharge. Because most people with COVID-19 on ventilation are not sedated to the same extent as typical intensive care patients, they can be more traumatised, and prevalence levels of PTSD as high as 96 per cent have been reported following ventilation as well as high levels of depression (Vindegaard and Benros 2020). Healthcare workers also report significant distress, with prevalence figures for clinical anxiety of around 23 per cent (Pappa et al., 2020) and for depression of around 34 per cent (Salari et al., 2020).

Treatment for COVID-19 is a developing story, involving increasing aggressive means of supporting breathing and increasing levels of oxygen in the blood:

1. Basic oxygen therapy: Patients are fitted with a mask and free-flowing oxygen-enriched air is piped through to help them breathe.
2. Pressurised oxygen therapy (POT): Patients are fitted with an airtight mask and receive pressurised oxygen-enriched air.
3. Mechanical ventilation: if POT proves ineffective, patients may move to mechanical ventilation in which a tube attached to a ventilator (which blows oxygen-rich air into the lungs and removes carbon dioxide) is inserted into the patient's mouth nose and down the trachea. Patients cans be lightly sedated, but high levels of delirium, confusion and agitation can result in the need for heavier sedation and the use of muscle relaxants.
4. Extracorporeal membrane oxygenation (ECMO): The final step, which bypasses the lungs to infuse the blood with oxygen directly in a process known as cardiopulmonary bypass.

Pharmacological treatment is limited at the time of writing, although a number of putative treatments are being trialled. The core treatment involves the use of an antiviral drug (e.g. remdesivir) which inhibits replication of the virus. It does so by inhibiting the action of RNA polymerase, an enzyme involved in the replication of viruses. Other drugs include monoclonal antibodies (essentially man-made antibodies) (e.g. REGN-COV, bamlanivimab, sotrovimab) for treatment of people with mild to moderate symptoms considered at high risk of clinical progression. These bind to the spike proteins on the virus cells, which prevent them from attaching to human cells and tag them for destruction. For patients who have progressed to a 'cytokine storm', a cheap and easily accessible drug, dexamethasone, helps reduce inflammation by inhibiting production of an enzyme, phospholipase A2, involved in a cascade of processes leading to cytokine production. Finally, due to its potential to cause blood clots, patients may be given so-called blood thinners such as heparin or enoxaparin to prevent their development.

## SUMMARY

- This chapter reviewed some of the anatomy and physiology relevant to health psychology and other chapters of this book. In the first section, it briefly described key functions of the brain and their situation within it. Key functional areas include:
    - the medulla oblongata, which controls respiration, blood pressure and heartbeat;
    - the hypothalamus, which controls appetite, sexual arousal and thirst. It also exerts some control over our emotions;
    - the amygdala, which links situations of threat and relevant emotions such as fear or anxiety, and controls the autonomic nervous system response to such threats.
- One of the key systems controlled by the brain is the autonomic nervous system. This comprises two parallel sets of nerves:
    - The sympathetic nervous system is responsible for activation of many organs of the body.
    - The parasympathetic nervous system is responsible for rest and recuperation.
- The highest level of control of the autonomic nervous system within the brain is the hypothalamus, which coordinates reflexive changes in response to a variety of physical changes, including movement, temperature and blood pressure. It also responds to emotional and cognitive demands, providing a link between physiological systems and psychological stress.
- Activation of the sympathetic nervous system involves two neurotransmitters – noradrenalin and adrenalin – which stimulate organs via the sympathetic nerves themselves. Sustained activation is maintained by their hormonal equivalents, released from the adrenal medulla. A second

system, controlled by the hypothalamus and pituitary gland, triggers the release of corticosteroids from the adrenal cortex. These increase the energy available to sustain physiological activation and inhibit inflammation of damaged tissue.

- The immune system provides a barrier to infection by viruses and other biological threats to our health. Key elements of the system include phagocytes, such as macrophages and neutrophils, which engulf and destroy invading pathogens. A second group of cells, known as lymphocytes, including cytotoxic T cells and B cells, respond particularly to attacks by viruses and developing tumour cells. Both groups of cells can collaborate in the destruction of pathogens through a complex series of chemical reactions.
- Slow viruses, including HIV, attack the immune system – by infecting CD4+ cells – and prevent the T and B cell systems from responding effectively. This leaves the body open to attack from viruses and cancers, either of which may result in life-threatening conditions.
- The immune system may, itself, cause problems by treating its own cells as external invading agents. This can result in diseases such as multiple sclerosis, rheumatoid arthritis and type 1 diabetes. Immune dysregulation is also implicated in some people's response to COVID-19, which can result in significant risk to life (see section on pulmonary diseases).
- The digestive tract is responsible for the ingestion, absorption and expulsion of food. Activity within it is controlled by the enteric nervous system, which is linked to the autonomic nervous system. Activity in the system is therefore responsive to stress and other psychological states. That said, some conditions thought to be the result of stress are now thought to be the result of physical as well as psychological factors. Gastric ulcers are thought to result from infection by *Helicobacter pylori*, while irritable bowel syndrome is no longer seen as entirely the result of stress but as having a multifactor aetiology of which stress is but one strand.
- The cardiovascular system is responsible for carrying oxygen, nutrients and various other materials around the body. Its activity is influenced by the autonomic nervous system. Two long-term 'silent' conditions that may lead to acute illnesses such as myocardial infarction or stroke are hypertension and atheroma. Both involve long-term processes. One way in which long-term hypertension may develop is by repeated short-term increases in blood pressure through the action of the autonomic nervous system in response to stress. Atheroma develops as a result of repair processes to the artery wall. Two obvious outcomes of this process are myocardial infarction, in which an artery supplying the heart muscle is blocked and dies. Angina presents with similar symptoms but is the result of spasm of the arteries and is reversible.
- Finally, the respiratory system is responsible for inspiring and carrying oxygen around the body, and the expulsion of carbon dioxide. It is prone to a number of disease processes, including chronic obstructive airways disease and lung cancer, all of which are significantly exacerbated by cigarette smoking. The latest pandemic virus, COVID-19, also acts primarily on the lungs, although more systemic and immune problems are also associated with infection with the virus.

## Further reading

Lovallo, W.R. (2005). Stress and Health. Biological and Psychological Interactions. Thousand Oaks, CA: Sage.

A relatively easy introduction to the autonomic and immune systems, as well as how stress can influence their activity.

Kumar, P.J. and Clark, K.L. (2012). *Clinical Medicine*. Oxford: W.B. Saunders.

At 1,304 pages, this is not a textbook you may want to buy (although shorter versions are available). But if you want to know more about the development of various diseases, this is an excellent starting point.

Vedhara, K. and Irwin, M. (eds) (2005). *Human Psychoneuroimmunology*. Oxford: Oxford University Press.

A readable guide to psychoneuroimmunology, written for those people who do not want to plough through £250, 400-page tomes (or so say the editors).

You can also find a wealth of information about illnesses and their treatment from the internet. Three excellent sites are:

medlineplus.gov/

This is a free service provided by the US National Library of Medicine and the National Institutes of Health

www.netdoctor.co.uk/

This service provides similar information and is also free.

www.patient.co.uk/

As above, provides free information.

In addition, many sites provide information on specific illnesses, including:

www.heartfoundation.org.au/index.htm – the Australian Heart Foundation

www.ulcerativecolitis.org.uk/ – the Ulcerative Colitis Information Centre

www.lunguk.org/ – the British Lung Foundation.

In fact, simply using the name of an illness as a search term in any search engine will undoubtedly allow you to access all the information you are likely to need about that illness and its treatment.

WEB

Visit the website at **go.pearson.com/uk/he/resources** for additional resources to help you with your study.

# Chapter 9

# Symptom perception, interpretation and response

## Learning outcomes

By the end of this chapter, you should have an understanding of:

- key theoretical models of symptom perception, interpretation and response
- contextual, cultural and individual influences upon symptom perception
- the core dimensions upon which illness can be represented
- the measurement of illness perceptions and their relationship with illness outcomes
- a broad range of influences upon symptom interpretation
- factors that influence delay in seeking health-care advice for symptoms

## Talking to a friend – has lay referral behaviour gone online?

When we experience a novel, unexpected or unusual bodily sensation or observe a change in our appearance, for example in our skin, research has shown that we typically mention it to a friend or family member to seek their view and advice as to whether or not to seek medical attention. This has been called ‘lay referral’ (the term ‘lay’ assumes of course that the person we talk to is not a medical expert who happens to be a friend or relative!). What the people we consult tell us can influence what we do next: whether we self-medicate or refer ourselves to the doctor; whether we relax and dismiss the signs as ‘nothing to worry about’; or ruminate about the bodily signs a bit longer before acting. Increasingly, we turn to search engines for online health forums, and over the past decade social media has also increasingly been used for seeking health advice. At times when casual social contact is restricted (such as during the COVID-19 pandemic) perhaps seeking advice online has become even more commonplace. The goal of this behaviour is information-seeking to help us make a decision about acting, however, what if the source we ask about our bodily changes is ill-informed and we relax when we shouldn’t? This chapter explores a range of personal, social and contextual factors that shape a person’s response to bodily signs or changes, which may or may not be symptomatic of an underlying illness. We examine delay in health-seeking behaviour as well as factors that may lead to the over-reporting of perceived symptoms – both behaviours have costs, the former to the individual, the latter to the healthcare system. However, talking to others about health concerns, whether face-to-face or online, can also bring benefits to the individual in terms of ‘not feeling alone’, and so perhaps the key factor here is ‘who’ do you talk to and how reliable and informed is what they tell you likely to be?

## Chapter outline

**How do we know if we are getting ill? Do we all react in the same way to symptoms? What influences how we perceive and interpret symptoms of illness? Do beliefs about illness differ across the lifespan? Do illness perceptions and their interpretation influence health-care seeking? These types of question are important to our understanding of how people cope with illness and of differentials in healthcare-seeking behaviour. They are questions that you need to ask yourself when thinking about the study of health and illness, whether as a future health psychologist or healthcare practitioner.**

## How do we become aware of the sensations of illness?

Illness generates changes in bodily sensations and functions that a person may perceive themselves or perhaps have pointed out to them by another person who says, for example, ‘You look pale’. The kind of sign that is likely to be noticed by the individual themselves includes changes in bodily functions (e.g. increased frequency of urination, heartbeat irregularities), emissions (such as blood in one’s urine), sensations (e.g. numbness, loss of vision) and unpleasant sensations (e.g. fever, pain, nausea). Other people may not notice these changes but would perhaps notice changes in bodily appearance (weight loss, skin pallor) or function (e.g. paralysis, limping, tremor). Radley (1994) distinguishes, as did MacBryde and Blacklow in a key early paper (1970), between ‘bodily signs’ and ‘symptoms of illness’. The former can be objectively recognised, but the latter requires interpretation: for example, a person has to decide whether excessive sweating (a bodily sign) is symptomatic of a possible health condition (e.g. influenza) or simply a sign of physical exertion.

While some diseases have visible symptoms, others do not and instead involve a subjectively sensed component of bodily responses, e.g. feeling sick, feeling tired, being in pain, which cannot be seen per se. Evidence from studies conducted in different countries point to high prevalence of physical symptom experience when self-reporting. For example, findings from a representative sample of Slovenian adults (Klemenc-Ketis et al., 2013, and see Figure 9.1) show that 71.4 per cent of men and 84.6 per cent of women had experienced at least one physical symptom in the past month, and in a national telephone survey conducted in New Zealand, people reported on average five symptoms a week (Petrie et al., 2014). Typically such surveys find the most common symptoms include back pain, joint pain, headache or fatigue (see IN THE SPOTLIGHT) , although the distribution of symptoms varied by gender (see Figure 9.1). While the majority of us will experience some symptom or another over the period of a month, only about one-third will actually seek medical attention, leading to what has been describes as ‘the symptom iceberg’ (Elnegaard et al., 2015). There is huge variability between individuals when it comes to attending to, or reporting, symptoms, and it is this variability that health psychologists are interested in.

As described in Chapter 1 ☛, people’s views about health are shaped by both their prior experience of illness and their understanding of medical knowledge, whether expert or lay. People therefore learn about health in the same way as they learn about everything else – through experience, either their own or of other people’s. People ‘fall ill against a background of beliefs about good and poor health’ (Radley, 1994: 61). Furthermore, Radley notes, people’s lives are ‘grounded in *activity*’, i.e. on the everyday activities or behaviour that depends upon the body, whether they be instrumental activities such as being able to run for a bus, or expressive activities like being able to look attractive. Illness can therefore challenge a person at a fundamental level.

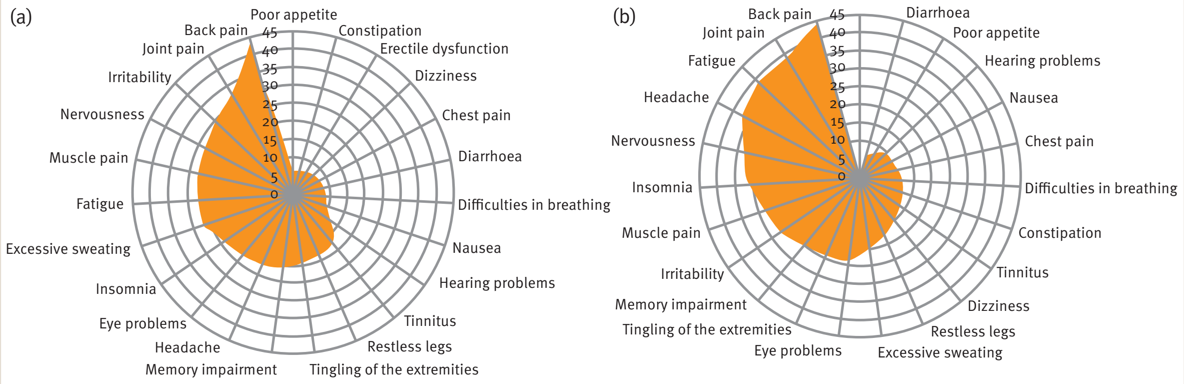


**Figure 9.1** The prevalence of self-reported symptoms (a) by men and (b) by women in the past month within a representative adult Slovenian sample

*Source*: Klemenc-Ketiš, Krizmaric and Kersnik (2013: 162).

## Illness or disease?

Cassell (1976) used the word 'illness' to stand for 'what the patient feels when he goes to the doctor', i.e. the experience of not feeling quite right as compared with one's normal state; and 'disease' to stand for 'what he has on the way home from the doctor's office'. Disease, then, is considered as being something of the organ, cell or tissue that suggests a physical disorder or underlying pathology, whereas illness is what the person experiences. People can feel ill without having an identifiable disease (think of a hangover!), and, importantly, people can have a disease and not feel ill (for example, well-controlled asthma or diabetes, early-stage cancer). A routine medical check-up may lead to a person who thought themselves healthy finding out that they are in fact 'officially' ill as indicated by the result of some routine test. By providing a diagnosis, doctors mark the entry of a person into the health-care system.

How does a person know if they are getting ill? This chapter will attempt to answer this by describing the processes underlying three stages of response:

1. perceiving symptoms;
2. interpreting symptoms as illness;
3. planning and taking action.

### WHAT DO YOU THINK?

How many of the symptoms below have you experienced in the last two weeks? Of those experienced, how many have you seen a health professional about? Think of the reasons why you did, or did not, seek medical advice about your symptoms.

- fever
- nausea
- headache
- tremor
- joint stiffness
- excessive fatigue
- back pain
- dizziness
- stomach pains
- visual disturbance
- chesty cough
- sore throat
- breathlessness
- chest pain.

## Symptom perception and interpretation

Many different stimuli compete for our attention at any given moment, so why do certain sensations become more salient than others? Why do we seek medical attention for some symptoms when we perceive them and not for others? As noted above, it has been shown that most adults will report experiencing some symptoms over a previous week or month, with often a significantly higher figure among women than among men, yet, independent of age and country of study, few will have sought medical attention – partly because most symptoms are transient and pass before we think too much about them, but also because people are not necessarily the best judges of whether their own perceived symptoms are in fact signs of illness.

Several models of symptom perception exist. The attentional model of Pennebaker (1982) describes how competition for attention between multiple internal or external cues or stimuli leads to the same physical sign or physiological change going unnoticed in some contexts but not in others. The cognitive–perceptual model of Cioffi (1991) focuses more on the processes of interpretation of physical signs and the influences upon their attribution as symptoms while also acknowledging the role of selective attention (Cioffi, 1991). We address both perception and interpretation here. Overall, research has highlighted an array of biological, psychological and contextual influences upon symptom perception (see Figure 9.2), with bottom–up influences arising from the physical properties of a bodily sensation, and top–down influences including attentional processes or a person's mood.

Once a symptom has been perceived, people do not generally consider it in isolation but relate it to other aspects of their experience and to their wider concepts

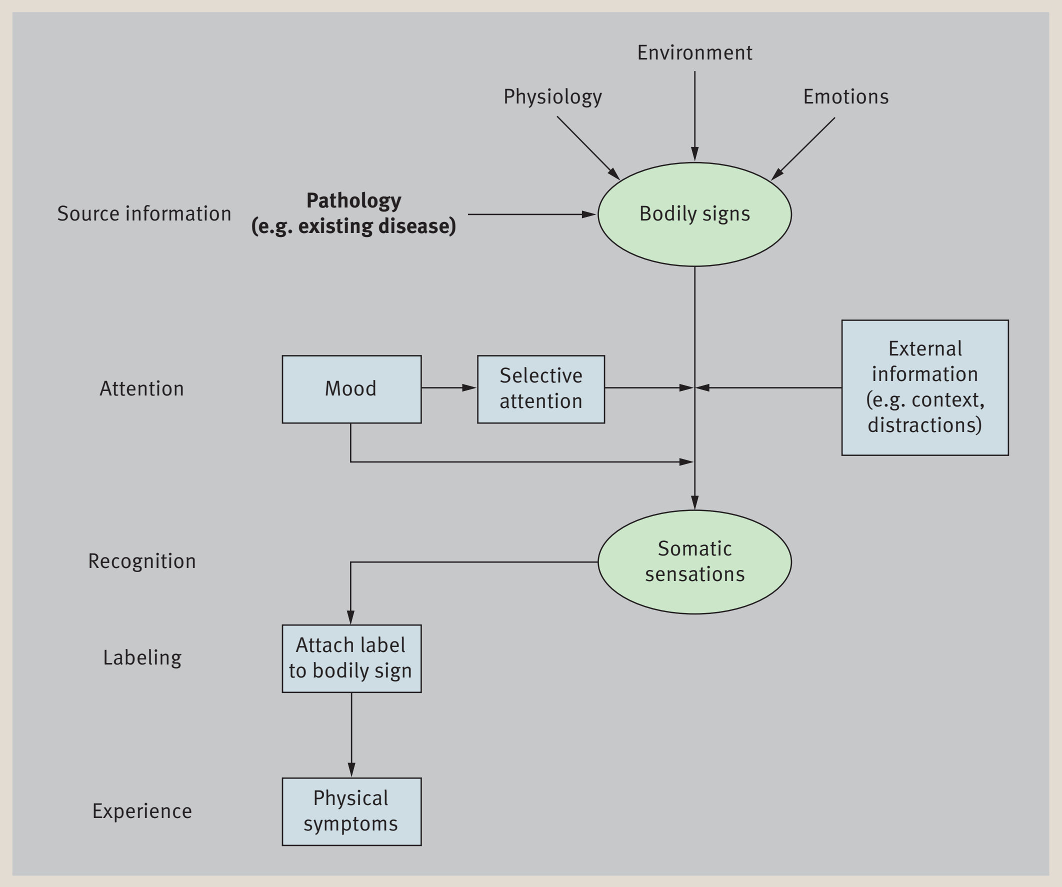


**Figure 9.2** A simplified symptom perception model

*Source*: Adapted from Kolk et al. (2003).

of illness. Symptoms are more than just labels; they not only derive from medical classifications of disease but can also influence how we think, feel and behave. Culture will influence the meanings and labels that individuals ascribe to symptoms (Stainton Rogers, 1991; Vaughn et al., 2009), as will other contextual and personal factors, as outlined below.

## Characteristics of bodily signs that increase symptom perception and interpretation

Bodily signs are physical sensations that may or may not be symptoms of illness: for example, sweating is a bodily sign, but it may not indicate fever if the person has simply been exerting themselves. Signs can be detected and identified, for example, blood pressure, whereas symptoms are what is experienced and, as such, they are more **subjective**, e.g. nausea (Cacioppo et al., 1989). Symptoms generally result from physiological changes with physical (somatic) properties, but the fact that only some will be detected by the individual highlights that biological explanations of symptom perception are insufficient. Those receiving a person's attention and interpreted as a symptom are likely to be:

- *Painful or disruptive*: if a bodily sign has consequences for the person, e.g. they cannot sit comfortably, their vision is blurred, or they can no longer perform a routine activity, then they are more likely to perceive this as a symptom.
- *Novel*: subjective estimates of the prevalence of a symptom significantly influence (1) the perceived severity attached to it and (2) whether the person will seek medical attention (see later). Experiencing a 'novel' symptom (new to oneself or believed not to have been experienced by others) is likely to be considered indicative of something rare and serious, whereas experiencing a symptom thought to be common leads to assumptions of lower severity and a reduced likelihood to seek out health information or care. For example, tiredness among students may be normalised and interpreted as a sign of late nights studying or partying, where it may, for some, reflect underlying disease. Coughing up blood however, or blood in one's urine is less typical, more likely to be considered serious and more likely to lead to seeking GP attention, particularly among younger persons (Elnegaard et al., 2015, 2017).
- *Persistent*: a bodily sign is more likely to be perceived as a symptom if it persists for longer than is considered usual, or if it persists in spite of self-medication.

subjective

personal, i.e. what a person thinks and reports (e.g. excitement) as opposed to what is **objective**. Subjective is generally related to internal interpretations of events rather than observable features.

objective

i.e. real, visible or systematically measurable (e.g. adrenaline levels). Generally pertains to something that can be seen, or recorded, by others (as opposed to subjective).

**Photo 9.1** This rash looks unpleasant, but is it a heat rash or something more serious?

*Source*: ian west/Alamy Stock Photo.

- *Pre-existing chronic disease*: past or current illness experience has a strong influence upon somatisation (i.e. attention to bodily states) and increases the number of other symptoms perceived and reported (e.g. Kolk et al., 2003; Chapman and Martin, 2011).

There are many trivial symptoms which do not require medical attention and which can be self-managed successfully without the costs associated with seeking health care (e.g. most flu episodes), but there are also some illnesses with few initial symptoms, such as cancer where seeking health care would confer significant advantage. Symptoms alone are therefore 'unreliable indicators of the need for medical attention' (Martin et al., 2003: 203) and, as we shall see in this chapter, are part of a complex interplay between biological, personal and psychological and sociocultural factors, again offering a challenge to purely biomedical thinking (Rosendal et al., 2013).

## The role of attentional states

Individual differences exist in the amount of **attention** people give to their internal state and external states (Pennebaker and Skelton, 1981; Pennebaker, 1982, 1992). Pennebaker discovered that somatic sensations are less likely to be noticed when a person's attention is engaged externally than when they are not otherwise distracted – the 'competition of cues theory'.

Think, for example, of an athlete going on to win a race in spite of having sustained a leg injury. On the other hand, individuals are more likely to notice tickling sensations in their throats and start coughing towards the end, rather than at the start, of lectures as attention begins to wane! Individuals are limited in their attentional capacity, so internal and external stimuli have to compete for attention thus a bodily sign may be noticed immediately in some contexts may remain undetected in others (Broadbent and Petrie, 2018). (This also points to findings that manipulating attentional focus, through cognitive or behavioural distraction, can be a useful form of symptom management) (see Chapter 13 ☛).

attention

generally refers to the selection of some stimuli over others for internal processing

A high degree of attention increases a person's sensitivity to new, or different, bodily signs. The portrayal of illnesses in the media can affect the attention we pay to our bodies and the interpretation or attributions we make to bodily signs. Massive increases are seen in those seeking healthcare advice at times of well-publicised outbreaks of illnesses, infections or toxin release: for example, chemical leaks, outbreaks such as the Ebola virus in 2014–15, or identification of new coronaviruses such as SARS in 2003, or SARS-CoV-2 (Garfin, Silver and Holman, 2020) The latter emerged in China in December 2019 with a disease known as COVID-19 and was subsequently declared a pandemic by the World Health Organization in March 2020. Garfin and colleagues describe how global media exposure to a health threat can heighten anxiety and lead to unnecessary help-seeking behaviours that can overburden healthcare systems. Worry about even tenuous links to the source of infection can heighten a person's attention to their own bodily signs and can produce the belief that they have contracted the illness. However, many people who seek medical attention at such times will find that there is no organic explanation for their symptoms. In extreme circumstances, media portrayal of illness can lead to what is called 'mass psychogenic illness'. This response illustrates the powerful effect of anxiety and suggestion on our attentional processes and the consequent perceptions and behaviour, i.e. our emotions interact with contextual cues to influence attention paid to bodily signs. Another example of external stimuli altering attention to, and processing of, bodily signs can be seen in what was described as 'medical student's disease' in the 1960s (Mechanic, 1962). In this case the increased knowledge about disease-specific symptoms obtained during medical lectures increases the self-reported experience of exactly those symptoms that they have just learnt about, most likely due to an increase in somatic awareness and attention being paid to one's bodily sensations (Broadbent and Petrie, 2018).

Brown (2004) distinguished between two attentional systems which are proposed to influence how symptom information is processed. The first, the primary attentional system (PAS), is proposed to operate below the level of consciousness and acts on stored representations, such as illness schema. When a person for whatever reasons over-attends to somatic (bodily) experiences any symptoms detected are automatically 'fitted' onto these schema – this can lead to a symptom being wrongly labelled, such as might happen in cases of 'mass psychogenic illness' or 'medical student's disease' referred to above. The secondary attentional system (SAS) on the other hand is considered more amenable to executive control, i.e. attention here can be manipulated by conscious thoughts and cognitive processes, such as rational weighing up of the likelihood of that person being affected by a certain condition i.e. one's perceived susceptibility. However, this secondary process is hampered if the PAS has already focussed the person's attention on a particular schema – if a 'label' has already been assigned to the symptoms, it can be difficult to shift. Furthermore, previous experience with an illness can increase a person's attentional bias. This is illustrated in an experimental study using an emotional Stroop task with threatening words relating to coronary heart disease as well as neutral, positive and other negative words. Those participants with a history of CHD showed clear attentional bias to CHD words and greater interference of such words on their response times, when compared to healthy controls (Ginting et al., 2013). The interference of CHD words was heightened in those CHD participants who also had higher anxiety, and, as stated already and again below, anxiety is commonly implicated in enhanced attention to potential or actual health threats.

Finally, attentional processes may be at play in the extent to which people manifest a **placebo response**, i.e. where a person reports an improved physical or psychological experience in spite of having received an inert, inactive or non-specific intervention. Described more frequently in samples experiencing conditions where there is pain (although also reported in other conditions), the placebo response is quite fascinating. Does the expectation of pain relief (perhaps enhanced by the language used by the healthcare professional administering or providing the active or the placebo drug) alter the attention paid to pain signals? Alternatively does the expectation of symptom relief reduce an individual's anxiety which affects the response to bodily symptoms, or do altered expectations and/or mood combine to reduce pain by some other, more physiological route? Amazingly it has been shown that even knowing that you have been administered a placebo does not prevent a positive effect on symptoms being reported as compared to those given no treatment; that even the type of treatment (injection vs pill), or the colour or branding of a pill, can influence the placebo effect; and that feelings a person holds towards their doctor can also influence it (Jarrett, 2019). Likewise a **nocebo** effect has been described whereby individuals can report symptoms or pathology in the absence of exposure to any pathogen – for example, if a person is told they may experience certain negative symptoms or side-effects from an inert substance, they may do so; or if they see another person display symptoms that can 'model' the same response in themself. Overall, it is evident from research that has been conducted that there are multiple influences on the placebo effect (Kirsch, 2018; Rossettini, Carlino and Testa, 2018 and see also Chapter 16 ☛ for a fuller discussion in relation to pain ).

## Social influences on symptom perception and interpretation

People hold stereotypical notions about 'who gets' certain diseases and this can interfere with perception and response to initial symptoms. For example, Martin et al. (2003) describe studies showing that the general public associate males with vulnerability to heart disease and not females, and that among heart attack patients, females less often recognised their initial bodily signs as symptoms of heart disease. The implications for health-care-seeking behaviour are obvious. Knowledge can also be lacking as to what constitutes symptoms of certain illnesses; for example 89 per cent of a Canadian sample were not aware that their symptoms were potential signs of head or neck cancer, and this too can cause delayed action (Queenan et al., 2016). Similarly, in an Irish sample women delayed twice as long as men in presenting with symptoms of a heart attack (Walsh et al., 2004), and although a gender effect on delay was not found in an Egyptian study, 89 per cent of those who delayed two hours+ in seeking help had misattributed chest pain symptoms to something else (Ghazawy, Seedhom and Mahfouz, 2015).

**placebo response**

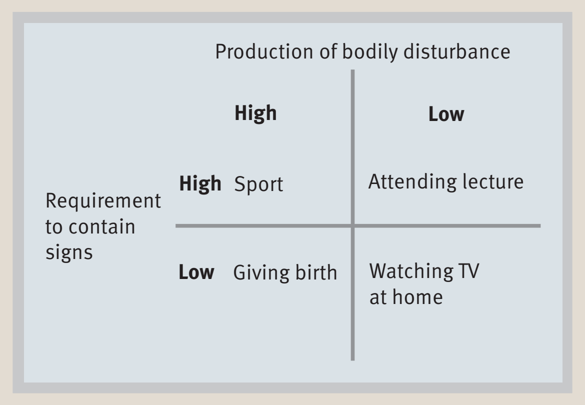
from the Latin 'to please' this describes a situation where a positive outcome or experience is reported in spite of receiving an inactive substance or intervention

**nocebo response**

the opposite of the placebo effect, from the Latin 'to harm' it describes a situation where a negative outcome or experience is reported due to a person's belief that they have been exposed to something harmful

More recently, in the early period of the COVID-19 pandemic media attention perhaps led us to expect that the elderly or physically vulnerable were more likely be infected and become ill. This potentially may have led to symptoms being dismissed, ignored or not reported.

Our motivation to attend to and detect signs or symptoms of illness will depend on the context at the time the symptom presents itself. As described above, people tend not to notice internal sensations when their environment is exciting or absorbing, but a lack of alternative distraction may increase perception of symptoms. Furthermore, situations and contexts bring with them varying expectations of physical involvement, as illustrated in Figure 9.3. Bodily signs, for example muscle spasms, when running a marathon or giving birth are expected and thus would not generally be considered symptomatic of illness; in contrast, few bodily signs are expected when sitting in lectures or watching TV, and unless a bodily sign (e.g. sharp back pain) can be attributed to posture or bad seating, it may be interpreted as a symptom of illness. In terms of expression, setting also plays a role, for example a sportsperson may not express their pain at the time, whereas very few people give birth silently; likewise listening in a lecture may deter a person from verbalising pain or discomfort, whereas pain when sitting at home watching TV may be expressed. Among children and adolescents there is also evidence that peer presence can influence the willingness to express symptoms, referred to as 'social display rules' by Hatchette et al. (2008). These authors conducted focus groups with Canadian adolescents aged 12–15 years old and found that reluctance to be removed from a social activity with peers, on account of a minor injury, led to concealment of pain and delayed symptom reporting.



| | | Production of bodily disturbance | |
|---|---|---|---|
| | | **High** | **Low** |
| Requirement to contain signs | **High** | Sport | Attending lecture |
| | **Low** | Giving birth | Watching TV at home |

**Figure 9.3** Situational differences in the production and containment of physical symptoms

*Source*: Adapted from Radley (1994: 69).

## The role of individual differences

The same bodily sign may or may not be perceived as a symptom in the first instance (due to factors such as gender, life stage, emotional state or personality traits). And even when a symptom has been detected, some individuals will maintain their everyday activities even when experiencing symptoms which would be perceived as debilitating to another person. This is because **individual differences** also exist in how symptoms are interpreted. The presence and characteristics of a physical sensation are insufficient explanations of why people end up in a healthcare system (Rosendal et al., 2013).

### Gender

It is often proposed that gender **socialisation** provides women with a greater readiness to attend to and perceive bodily signs and symptoms; however, the evidence appears to vary according to the symptoms explored (Macintyre et al., 1996; Young, 2004). Somatisation disorder, i.e. the experience of multiple or medically unexplained symptoms (see 'In the spotlight'), is however more common in females (Noyes, 2001) and women tend also to score higher on measures of neuroticism (Williams, 2006). This, and the presence of gender socialisation, suggests that women will interpret a bodily sign as symptomatic of underlying illness more than men. Evidence bears this out inasmuch as women are seen to present to health services more frequently (Eurostat, 2007); however, few studies have explicitly compared men and women who have been matched in terms of other influences on symptom interpretation (such as personality,

**individual differences**
aspects of an individual that distinguish them from other individuals or groups (e.g. age, personality

**socialisation**
the process by which a person learns – from family, teachers, peers – the rules, norms and moral codes of behaviour expected of them

social context, etc.), with gender often being controlled for in analysis rather than explicitly examined. Where gender differences are highlighted, such as in some studies of illness perceptions, we have included them.

Hale and colleagues find evidence of men 'avoiding' information about illness even when they are faced with it in the media. A qualitative study of symptom perception and reporting behaviour of men with prostate disease found four themes emerged from interviews: 'living up to the (masculine) image'; 'normal or illness?' (re symptom interpretation); 'protecting the (masculine) image'; 'engaging with the system'. These themes encompass men's accounts of learning to ignore (and hide) symptoms out of a need to be seen to be strong and masculine, point to a lack of understanding about urination problems (e.g. urgency, dribbling) being symptoms of prostate illness as opposed to part of ageing, and highlight men's unwillingness or anxiety about talking to family or friends about their 'embarrassing' symptoms or taking them to a healthcare professional (Hale et al., 2007). van Wijk and Kolk (1997) have suggested that as male-directed media is less inclined to provide health advice than women's media, males may have less developed illness cognitions which reduces their likelihood of perceiving a bodily sign as a 'symptom' and limits their reporting behaviour (see later).

A special issue in *The Psychologist* on the issue of male psychology featured an opening paper entitled 'Being a man – putting life before death' (Seager and Wilkins, 2014). This taps into a large body of evidence that suggests that men are typically overrepresented in figures attached to health-risk behaviours (see Chapters 3 to 5 ☛). In addition, men generally also perceive, respond and act on bodily signs and symptoms differently to women and delay longer, or avoid altogether, communicating health concerns or seeking healthcare (see review by Yousuf, Grunfeld and Hunter, 2015). None of the empirical differences noted confirm that issues of health, or indeed death, are *less important* to men – the difference may lie in how men express their needs or how they are supported in (not) doing so. *The Psychologist's* special feature addresses a gender inequality which, it is proposed, society may ignore. At many and various points throughout this textbook, we highlight gender differences where they exist; however, that is not quite the same as highlighting gender inequalities. If we do that, we should ensure we look at inequalities in both directions – male and female. Are health and social care services in effect 'gender-blind' in a way that is more disenfranchising for men than they are for women? Are such services male-friendly? Are men 'allowed' to express feelings of vulnerability or concern about any physical (or mental) health symptoms they experience? The series of articles Seager and Wilkins introduce are thought provoking and well worth a read as we encourage more critical thinking around gendered identities and roles in an evolving discipline of health psychology.

Such gender differences are not confined to adults – the focus group study of adolescents, reported by Hatchette and colleagues (described above) revealed similar differences, whereby female adolescents felt 'freer' to discuss pain symptoms than did males who expressed pain more cautiously.

In considering gender differences in symptom perception and interpretation, there are many overlapping explanations, although it is generally acknowledged that differences exist in the extent to which males and females are 'allowed' to respond to bodily signs in terms of social norms. It may also be that physiological differences arising from puberty and menstruation influence **pain thresholds** in the first place, or perhaps the evidence that women talk about symptoms more and attend health care more does not reflect so much a gender difference in symptom perception as one in reporting behaviour (see later section).

## Life stage

With age comes experience and typically an increasing awareness of one's internal organs, their functions and sensations. While there are age differentials in concepts of health and illness (Chapter 1 ☛), do age differences in symptom perception and interpretation contribute to identified differentials in health-care-seeking behaviour? As described in Chapter 1 ☛ children develop a conceptual understanding of illness during the course of their cognitive development and socialisation, but whether children perceive specific symptoms differently to adults is unclear. The limited language of very young children

pain threshold

the minimum amount of pain intensity required before it is detected (individual variation) presents challenges to parents, researchers and health professionals alike. In the absence of language, crying, rubbing or other nonverbal behaviour is relied upon by adults as indicating symptom experience in the very young: pain, for example, is exhibited rather than reported. It is likely, however, that the child's own symptom perception is influenced by similar attentional, contextual, individual and emotional influences as seen in adults, Indeed, it has been shown that the presence of problems in attention, concentration and impulsivity may be related to reduced symptom perception and asthma outcomes (McQuaid et al., 2007; Koinis-Mitchell et al., 2009).

It is likely that young children are distinct from adolescents in their cognitive awareness of illness and its implications by virtue of the stage of cognitive development attained **(see Chapter 1 ☛)** but also by virtue of the difference in life or illness experience and knowledge accumulated. Studying the symptom perceptions and interpretations of very young ill children is challenging, for various reasons, including ethical issues in submitting sick children to the demands of face-to-face interviews, methodological issues such as the limited availability of child validated assessment tools, or the challenges of limited linguistic and cognitive skills. However, multidimensional illness constructs have been reported among children and young adults considering acute and less serious conditions (e.g. the common cold, Koopman et al., 2004), their own serious and chronic conditions, such as CFS (Gray and Rutter, 2007), asthma and eczema (Walker et al., 2006), and illness in others, such as their mother's cancer (Forrest et al., 2006). In this latter study, children aged 6 to 18 years talked about their mother's breast cancer, and mothers also talked about how they thought their child perceived the cancer and its treatment. Children's ideas about cancer included seeing it as common, as rare, as a killer, as treatable, as something that can be genetic, caused by smoking, worsened by stress; and ideas about treatment included thinking that the more treatment received the worse the cancer, but the less likely it would be to come back. Mothers were not always aware of how much their child understood about the illness and its treatment and, indeed, many found communicating about treatment implications or potential life-threatening consequences of the cancer difficult. When illness is in the family **(Chapter 15 ☛)**, communication and shared understanding of symptoms or treatment is an important factor in aiding adaptive coping with illness, both for the 'ill' person and for those affected by it.

At the other end of the age spectrum, ageing populations certainly bear the burden of many chronic or life-threatening diseases, such as heart disease, stroke, arthritis and breast cancer, but there is limited evidence of an age effect on symptom perception, with some studies finding that increasing age tends to be associated with increased symptom self-report (e.g. Bardel et al., 2009). Older adults may however interpret and respond differently to symptoms when perceived however, for example with greater delay in presenting with breast cancer or acute myocardial infarction symptoms (Grunfeld et al., 2003; McKinley, Moser and Dracup, 2000) (see Chapter 2 ☛).

## Cultural influences on perception and interpretation

We have heard in earlier chapters about cultural variations in health behaviours and in the incidence of certain diseases, (for example, a four times higher incidence of diabetes among South Asian populations, Dreyer et al., 2009). Cultural variation has also been shown to exist in the extent to which individuals respond to perceived physical symptoms, although the extent to which differences can truly be ascribed to culture is not always clear, given that the range of other influences (e.g. age, gender, illness experience) are not always controlled for in studies. However a recent review of studies has pointed to consistent findings of higher pain intensity ratings both pre- and post-operatively among African American and Hispanic individuals compared with non-Hispanic whites (Perry et al., 2019). It is likely that some of the reported cultural differences can be ascribed to gender identity and gendered role – which also vary in cultures. For example older American studies compared samples of pain patients by virtue of their Jewish, Italian, Irish or 'old' American (those of Anglo-Saxon descent) origin. Italian Americans expressed pain more than Irish or 'old' American men but felt less free to do so in the home, as they wanted to project the image of being the strong 'head of the family'. Irish Americans stoically accepted or denied their pain, again reflecting a socialised gender phenomenon. The 'old' Americans removed any emotional content from their pain expression, reporting their pain in a factual way – these men saw emotional expression as a likely hindrance to the doctor's knowledge, skill and efficiency in treating them, furthermore the wives of 'old' American men reacted with either embarrassment or concern if their husbands expressed emotional responses to their pain. Zborowski (1952) stated that such cultural variations are learned during socialisation, where people's ideas about what is acceptable pain to bear and express is shaped. Pain expression has a social function – expressing pain or reporting symptoms can also serve to elicit support and thus can be considered adaptive (see discussion of lay referral and also Chapter 16 ☛).

## The role played by emotions and personality

Generally, mood is crucial. People who are in a positive mood tend to rate themselves as more healthy and indicate fewer symptoms, whereas people in negative moods report more symptoms, are more pessimistic about their ability to act to relieve their symptoms and believe themselves to be more susceptible to illness (Leventhal et al.,1996). According to the classic symptom perception hypothesis, a predisposition to experiencing negative emotions such as seen in those displaying **neuroticism** (N) or **negative affectivity** (NA) will likely increase experience and reporting of a greater number of symptoms (Watson and Pennebaker, 1989; Cohen et al., 1995) (see Chapter 16 ☛). Neuroticism is described as a trait-like tendency to experience negative emotional states and is related to the broader construct of NA which can manifest itself either as a state (situation-specific) or a trait (generalised). State NA can incorporate a range of emotions, including anger, sadness and fear. Trait NA, as with neuroticism, has been found to affect the perception, interpretation and reporting of symptoms. In terms of perceptual style, neurotics and those high in trait NA are more introspective and attend more negatively to somatic information and thus this attention leads to more frequent symptoms or bodily changers being noted, which are also then more likely to be misattributed to underlying disease (Williams, 2006). Combining trait negativity with worrying about one's health condition has been shown to not only make it more likely that a person will detect bodily symptoms, but for these symptoms to be interpreted as being attached to the condition the person has, for example, as shown among those with asthma (Mora et al., 2007). As a result of their negative interpretations of symptoms, individuals who score highly on N or NA are more likely to seek healthcare than those low in N. However, neuroticism is not all bad: there is evidence that moderate levels of neuroticism can benefit health: for example, in terms of better adherence to treatment or quicker presentation to medical services following actual illness events (see Williams, 2006, for a fuller discussion).

### neuroticism

a personality trait reflected in the tendency to be anxious, feel guilty and experience generally negative thought patterns

### negative affectivity

a dispositional tendency to experience persistent and pervasive negative or low mood and self-concept (related to neuroticism)

Quite often, studies have implied a link between trait N and hypochondriasis, where there is a preoccupation with being ill based on misattributions and misinterpretations of bodily signs as symptoms (Ferguson, 2000). This suggests that the symptom perception is unfounded in terms of actual physical symptoms; however, Williams (2006) points to a body of evidence where neuroticism is in fact associated with greater physiological reactivity to stress, including elevated levels of stress hormones such as cortisol (see Chapter 11 ☛). In some circumstances, therefore, there may be a 'real' or objective pathway between N and increased symptom experience.

Looking more broadly at negative emotional states, particularly anxiety or depression, there is evidence also that these mood states may increase symptom perception by means of affecting attention, and increasing rumination and recall of prior negative health events, which increases the likelihood of new bodily signs being viewed as symptoms of further illness. Hyper-vigilance in terms of over-attending to somatic sensation has been seen among cancer survivors, where fear of recurrence can increase a person's attentions and responsiveness to bodily signs, in the hope of detecting any bodily changes at an early stage (Heathcote and Ecclestone, 2017). In contrast, fear of being diagnosed with a potentially serious illness can reduce a person's attention to and consideration of possible meanings of their symptoms, such as reported among men with prostate problems who downplayed symptoms out of fear of finding disease (Hale et al., 2007). Interestingly it has been shown in a series of experimental studies that anxiety and depression may behave differently when it comes to symptom perception, with depression implicated in inflated retrospective recall of symptoms, and anxiety more associated with concurrent symptom reports (Howren and Suls, 2011).

**Photo 9.2** A 2020-2021 phenomena: awaiting COVID-19 vaccination

*Source*: Christopher Furlong/Getty Images News/Getty Images.

It is worth noting however that while experimental and observational longitudinal evidence of the effects of negative emotions on symptom perception exists, the bidirectional relationship between mood *states* and symptom perception and interpretation needs further exploration.

## Self-identity

Levine and Reicher (1996) proposed an account of symptom evaluation based on self-categorisation theory (e.g. Turner et al., 1987), which highlights the importance of **social identity**. Most people have several social identities depending on context (e.g. student/partner/daughter), and it is proposed that the interpretation of symptoms differs depending on a person's current salient social identity. They demonstrated this in a series of studies which manipulated the salient identity a participant was to consider an illness or injury scenario within, and examined the perceptions of threat the illness scenario generated. For example, female teacher-training students specialising in PE (physical education) evaluated scenarios differently depending on whether they were in a condition that identified them by gender or as a PE student. In two further studies that could now be considered as rather gender stereotypical, the identity of female secretaries and rugby-playing males was manipulated to enhance either the gender salience or the occupational salience, in addition to manipulating where the illness threat lay (e.g. threat to attractiveness, occupation, emotionality; or physicality). Each manipulation affected the perception of illness threat. Although participants in Levine's studies were dealing with hypothetical illness/injuries in an artificial experimental setting, the reality is that most people fulfill a variety of social roles, and therefore it is logical to suppose that salient identity may differ in different contexts, with potential effects upon symptom perception and interpretation. More recently, St Clair and colleagues (St Clair, Clift and Dumbleton, 2008) confirmed the role played by self-categorisation and social identity in symptom experience, finding in two experimental studies that symptom severity was rated more highly when study participants were manipulated to have enhanced salience of relevant illness group membership. The implications

social identity

a person's sense of who they are at a group, rather than personal and individual, level (e.g. you are a student, possibly a female).

of self-categorisation for symptom experience could be important, yet are rarely studied – for example self-identification with a particular illness group may worsen perceived symptoms, and potentially interventions that support movement from one self-categorisation (e.g. person with cancer) to another (healthy person) is likely to be reflected by changes in symptom perception, interpretation, and response.

## Coping style

How people characteristically think and respond to external or internal events can also influence symptom perception and interpretation. For example, there is some evidence that individuals who cope with aversive events by using an emotion-avoidant the cognitive defence mechanism of **repression** are less likely to experience and report symptoms than non-repressors, possibly due to the experiential avoidance, and that this may explain an association reported between repression and certain disease (e.g. hypertension, Casagrande et al., 2019; Mund and Mitte, 2012).

**repression**
a defensive coping style that serves to protect the person from negative memories or anxiety-producing thoughts by preventing their gaining access to consciousness

**IN THE SPOTLIGHT**

### Medically unexplained (physical) symptoms MU(P)S

It is thought that between 30 per cent and 50 per cent and between 40 per cent and 60 per cent of symptoms presenting to primary or secondary care respectively are unexplainable (Nimnuan et al., 2001; Khan et al., 2003). Defined as persistent bodily symptoms with functional disability evident in the absence of any explanatory pathology (Chalder and Willis, 2017), the estimated healthcare cost of MUS, in England alone, is around £3 billion per year, with roughly 42 million work days lost due to these health complaints (Bermingham et al., 2010). There are many different symptoms that cluster to make up MUS, and many of these symptoms, including fatigue, gastrointestinal discomfort, pain, are common to a range of disorders,– for example, Chronic Fatigue Syndrome, Irritable Bowel Syndrome, Fibromyalgia, chronic pain. MUS can be highly distressing and debilitating to a person's physical functioning and global quality of life. Where symptoms are not attributed to anxiety, depression, or other psychiatric disturbance, MUS are often diagnosed as somatic symptom disorders (American Psychiatric Association, DSM V, 2013). There is evidence that MUS presents a significant challenge to healthcare professionals, who predominantly work within a biomedical model (see Chapter 1 ☛) and who seek an explanation for symptoms that offers an avenue for medical treatment, which, by definition, is typically not forthcoming, with MUS. Stone (2014) emotively describes how these patients can elicit feelings of 'heartsink' in the family practitioner. Furthermore, medical professionals' communications to patients about their 'unexplainable' symptoms can undermine a patient's sense of satisfaction in the HCP's competence, while also failing to validate their concerns. This can contribute to further distress (Weiland et al., 2012; Stone, 2014). Worryingly it has been described how the same symptoms, for example persistent pain and fatigue (lasting 3–6 months typically, an arbitrary cut-off) presented to a different specialty depending on where your GP (general practitioner) has referred you to, can result in a different diagnosis – for example, a referral to internal medicine = Chronic Fatigue Syndrome; a referral to rheumatology = fibromyalgia; a referral to psychology or psychiatry = Somatoform Disorder (Judith Rosmalen, 2014, personal communication). Diagnoses are not uncommonly amended (Eikelboom et al., 2016) and of course, differential diagnoses lead to different treatment intervention pathways.

Research in fact points to an array of influences including genetic, psychophysiological relational (poor attachment and early conflict) and social as well as

*(continued)*

those cognitive processes of attention and memory described in this chapter (Brown, 2004, 2013; Chalder and Willis, 2017). There is also consistent evidence of a strong association between MUS and psychological disorders including anxiety and depression.

In terms of treatment, in 2011 the UK Royal College of General Practitioners and the Royal College of Psychiatrists highlighted a need for patients' accounts of their symptoms to be taken seriously with a focus on how to manage them to improve functionality for the benefit of wellbeing. They noted that recognising that MUS exist and that treatment can use a combination of medical (e.g. pain medication) and behavioural (e.g. exercise, relaxation) approaches will work to the benefit of both patient and HCP. More recently it has been noted that, given the association with negative mood states, the optimal treatment is likely to be one that takes a more holistic and psychosocial approach, for example Cognitive-Behavioural Therapy (Chalder and Willis, 2017). CBT and also programmes of tailored self-help, have reported successes; for example a systematic review and meta-analysis of findings from 18 controlled trials comparing self-help with usual care found reduced symptom severity (17/18 studies) and improved quality of life (16/18 studies) (van Gils et al., 2016).

The label of MUS itself is 'dualistic' (see Chapter 1 ☛) in its suggestion that the mind and the body are separate and that medicine has nothing to offer these symptoms, and the term 'multiple somatic symptoms' may be a more preferable biopsychosocial term (Creed et al., 2012). Whatever the label, given the prevalence and the huge personal and social cost attached to these symptoms and symptom clusters, it should come as no surprise that the need for improved health-care professional training in how to best manage those affected by MUS has been highlighted.

An alternative explanation could be found in the reported associations between repression and higher levels of **comparative optimism** regarding controllable health threats, such as tooth decay, which may have led to reduced preventive behaviours (Myers and Reynolds, 2000).

A further distinction has been drawn between monitoring and blunting coping styles (Miller et al., 1987). **Monitors** deal with threat by monitoring their situation for threat-relevant information, whereas **blunters** ignore or minimise external and internal stimuli. Where one stands on this dimension will influence symptom perception as well as determine how quickly a person uses health services (see below).

**comparative optimism**

initially termed 'unrealistic optimism', this term describes an individual's estimate of their risk of experiencing a negative event compared with similar others (Weinstein and Klein, 1996)

**monitors**

this generalised coping style involves attending to the source of stress or threat and trying to deal with it directly, e.g. through information-gathering/attending to threat-relevant information (as opposed to blunters)

**blunters**

this general coping style involves minimising or avoiding the source of threat or stress, i.e. avoiding threat-relevant information (as opposed to monitors)

## Illness experience

It is not perhaps surprising that prior experience affects the interpretation of and response to symptoms. Having a history of particular symptoms or experience of illness in others (i.e. vicarious experience) generates assumptions about the meaning and implications of some symptoms. Also, as previously stated, symptoms considered to be rare in either one's own experience, or in that of others, are more likely to be interpreted as serious than a previously experienced or widespread symptom (Croyle and Ditto, 1990). Believing symptoms to be 'just a bug that's going round' can mean that people sometimes ignore potentially dangerous 'warning signals'. A knowledge of which bodily signs are associated with particular behaviour or illnesses (e.g. sweats and flu, sweats and exercise) will enable interpretation and attachment of a meaning to the symptom. These reserves of knowledge are known as 'disease prototypes'. Relevant to the ongoing (at the time of writing) coronavirus outbreak is the earlier finding that people tend to perceive novel viral threats as higher in risk compared to more common threats such as influenza (Hong and Collins, 2006).

Given all the above influences upon symptom perception and interpretation, it is not perhaps surprising that a core area of research within health psychology has been the development and testing of models of illness behaviour. These models have focussed primarily upon cognitive and emotional responses that influence a person's 'self-regulation' and coping responses in an attempt to 'restore normality'. As you will see in subsequent sections, research has also increasingly considered wider sociocultural influences.

## Illness/disease prototypes and a 'common sense model' of illness

Even when a physical sensation or bodily sign is perceived as a 'symptom', what is it that leads a person to believe they may be ill? This arises when the symptoms a person is experiencing 'fit' a model of illness retrieved from their memory. It is here that health psychology draws from models dominant in cognitive psychology. Symptoms are placed in the context of a person's past knowledge and experience which has led to the development of protypical expectations of certain illnesses, for example of the common cold. When getting that first 'sniffle', matching or not matching those symptoms to your 'common cold' prototype will shape how you perceive the 'sniffles' and whether they are perceived to be symptoms of illness or not, and this will activate a mental model of how symptoms are then interpreted and responded to.

Illnesses that have clear sign-sets (symptoms) and prototypes associated with them are more likely to be easily recognised in self-diagnosis: for example, a person experiencing mild chest pain may quickly consider indigestion; a lump found in the breast would, generally, prompt concerns that it may signify cancer and result in health-care seeking. This is generally the case (see Chapter 4 ☛ for a discussion of influences on breast-screening behaviour), however, there are other symptoms of breast cancer, such as breast pain or skin scaling around the nipple, that may not be in a person's 'prototype', and thus such symptoms may go unidentified. This inability to correctly identify various potential breast cancer symptoms predicted help-seeking delay among a general population sample of 546 women (Grunfeld et al., 2003). Relevant to this, Cacioppo et al. (1989) pointed to the notion of 'salience', i.e. some symptoms will be 'tagged' to strong and emotive labels in our memory stores, e.g. cancer, heart attack, whereas others will be less so, e.g. menstrual cramps, indigestion. He reports data whereby women with gynaecological cancers had initially been more likely to consider less-threatening explanations for their symptoms, e.g. menopause, than they were the most negative interpretation of their symptoms, i.e. cancer, and had only accepted cancer as a possibility (leading them to seek health care) when symptoms had worsened. In this early, influential paper Cacioppo also notes that the 'more non-descript the sign or symptom, the greater the number of potential matches in long-term memory and the greater tends to be the likelihood of making errors when linking these bodily events to a particular physiological condition' (p. 260). Similarly, Perry et al. (2001) report that when heart attack symptoms do not 'match' the existing illness prototype in terms of severity, delay in seeking medical attention is greatest. Furthermore, there is evidence that a failure of a symptom to fit a protypical image of the 'likely victim' of a particular symptom can lead to misinterpretation or delay, as seen where women were less likely to attribute chest pain to a possible heart attack, as their stereotypical image of a heart attack victim was male (Martin et al., 2004). One's own experience, but also observation and input from others, and social comparison, can help shape a person's prototypes.

These prototypes have given rise to what is often described as 'common-sense models of illness', examples of which are contained in Table 9.1. With regards to a

**Table 9.1** Disease prototypes

| | Influenza | COVID-19 |
|---|---|---|
| Identity | Runny nose, fever, shivery, sneezing, aching limbs | A high temperature/ fever, a new continuous cough, loss or change in sense of taste or smell, shortness of breath, fatigue |
| Cause | Virus | Virus |
| Consequences | Rarely long-term or serious (except if new 'strain') | Unlikely serious consequences depending on age and health status/comorbidities, but potential serious respiratory impact, possible death, uncertainty around Long-COVID following even mild illness |
| Timeline | 24 hours to a week | Months to years (growing evidence around Long-COVID) |
| Cure | Time and self-medication | Mild disease – time and self-medication, serious disease multiple treatments including oxygen, potential ventilation |
| Type of person | Anybody | High-risk groups with pre-existing conditions, obesity; anyone for milder disease |

'new' illness, such as COVID-19, our disease prototypes are evolving as fuller understanding of symptoms, their timeline and available treatments grow.

## Illness representations and the 'common-sense model' of illness

Many different terms are employed, sometimes interchangeably, by authors discussing illness models: for example, cognitive schemata (Pennebaker, 1982); **illness cognition** (Croyle and Ditto, 1990); personal models (Lawson et al. 2007) and illness perceptions (Weinman et al., 1996). Probably the most commonly applied and tested common-sense model of illness is the self-regulatory model of illness and illness behaviour proposed by Howard Leventhal and colleagues, typically also referred to as 'the common-sense model, CSM) (Leventhal et al., 1980, 1984, 1992, 2003). In this model, illness cognitions are defined as 'a patient's own implicit common-sense beliefs about their illness' (e.g. Leventhal et al., 1980, 1992) and these mental representations provide a framework for understanding and coping with illness, and help a person to recognise what to look out for.

Leventhal and colleagues propose a dual-processing model (see Figure 9.4), which considers in parallel the cognitions triggered by objective components of the stimuli, e.g. the symptom is painful, and the subjective emotional response to that stimulus and the associated cognitions that arose, e.g. anxiety. This model suggests that active processing of this cognitive and emotional 'representation' elicits a coping response thought to be appropriate. Coping efforts, if subsequently appraised as being unsuccessful, can be amended, or alternatively the initial representation of the stimuli/health threat can be revisited and amended. For example, if a person experiences a headache that they believe is a hangover, they are unlikely to be too worried about it and may simply self-medicate and wait for the symptoms to pass. If the symptoms persist, however, they may rethink their coping response (e.g. go to bed), or rethink their initial perception (e.g. maybe this isn't a hangover) and thus alter their coping response (e.g. go to the doctor's). The existence of feedback loops from coping to representations and back again contributes to the model being called

illness cognition

the cognitive processes involved in a person's perception or interpretation of symptoms or illness and how they represent it to themselves (or to others) (cf. Croyle and Ditto, 1990)

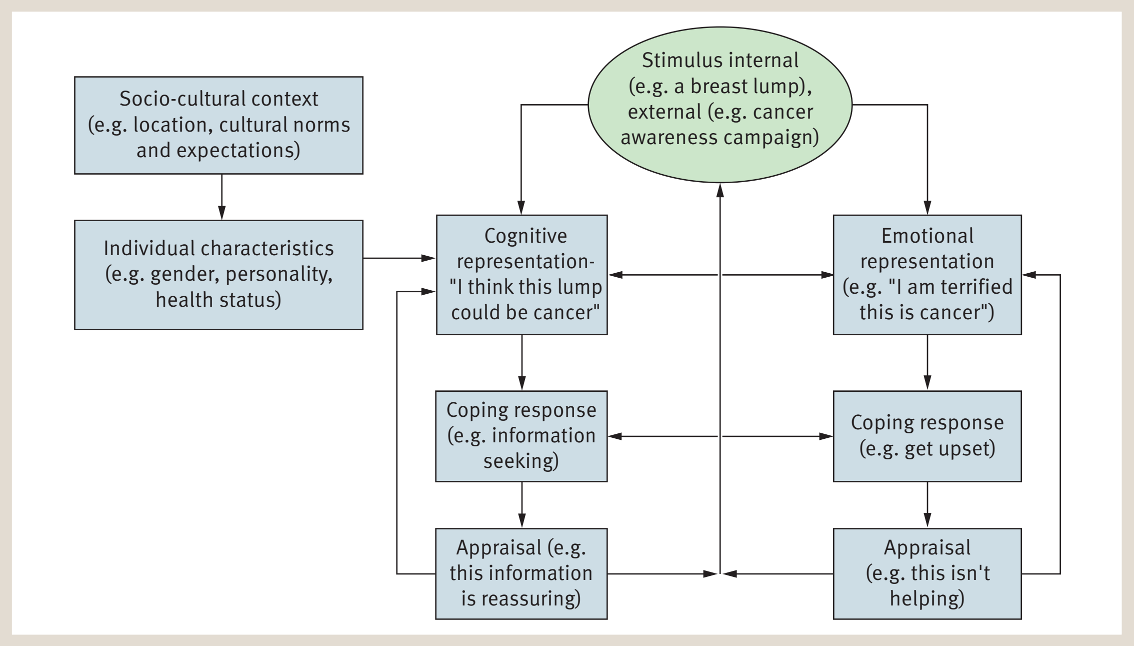


**Figure 9.4** The 'common-sense model of illness' as applied to self-detection of a breast lump

*Source*: Leventhal et al., 1992.

'self-regulatory', with self-regulation simply meaning that an individual makes efforts to alter their responses (appraisals or coping responses) in order to achieve a desired outcome, such as a return to their 'feeling normal'.

Detailing this model further, the cognitive side of the model contains mental representations of illness (illness representations – typically referred to as IRs) emerge as soon as a person experiences a symptom or receives a diagnostic label. At this point they start a memory search to try to make sense of the current situation by retrieving pre-existing illness schemata with which they can compare. IRs are acquired through the media, through personal experience of illness or that of family and friends and, as prototypes, they can be vague, inaccurate, extensive or detailed. Any new symptom may be matched to a pre-existing model or 'prototype' of illness that the person holds, and obviously as mentioned at the start of this section, mistakes can be made, for example, 'matching' chest pain wrongly to previously experienced indigestion could be dangerous if it is in fact a heart attack.

Five consistent themes were found in the content of IRs reported in early development work asked open-ended questions of people suffering from a range of common conditions, including the common cold (Lau et al., 1989), cancer or diabetes (Leventhal et al., 1980). These have subsequently been confirmed in many quantitative studies, some of which will be mentioned below. The five IR dimension s are:

1. *Identity*: Illnesses are identified by a label, by the presence or absence of concrete signs and concrete symptoms. For example, 'I feel shivery and my joints ache, I think I have flu'.
2. *Consequences*: the perceived physical, emotional, social, economic or other impact of an illness on life. Consequences can appear in combination, for example, 'Because of my illness I won't be able to go to the gym today so I won't see my friends' or 'Because of my illness I will have to take early retirement and lose my income'.
3. *Cause*: the perceived cause(s) of illness may be biological (e.g. germs), emotional (e.g. stress, depression), psychological (e.g. mental attitude, personality), genetic or environmental (e.g. pollution), or as a result of an individual's own behaviour (e.g. overwork, smoking). Some of these causes may overlap, e.g. stress and smoking behaviour, and may overlap with **attributions** of cause made after the onset of illness (e.g. French et al., 2001, 2002).
4. *Timeline*: the perceived time-frame for the development and duration of the illness. Can be acute (or short-term, with no long-term consequences), chronic (or long term) or episodic (or cyclical). For example, 'I think my flu will last only three or four days' or 'My pain comes and goes'.
5. *Curability or controllability*: the extent to which individuals perceive that they, or others (e.g. family, healthcare professionals) can control, treat or limit progression of their illness. For example, 'If I stop smoking it will help to reduce my cough' or 'The doctor will be able to cure my cough by prescribing an antibiotic'. This dimension may be particularly relevant for those facing chronic symptoms or illness.

Before reviewing some of the research using this framework it is worth first describing the evolution on how illness representations have been measured and how the initial 5 domains have been extended.

## Measuring illness representations: The Illness Perception Questionnaire (IPQ, IPQ-R (revised) and the Brief IPQ)

Opinions vary about how best to elicit and assess individuals' privately held illness perceptions and beliefs. The use of open-ended interviews as a method of eliciting illness representations (as used in Leventhal and colleagues' early work) led to the criticism that questions such as 'To what extent when thinking about your illness do you think about its consequences?' may well be leading. Furthermore, interviews are very time consuming and generally restrict sample size, although some studies have managed to successfully employ open-ended questioning (using prompts where necessary) (e.g. Forrest et al., 2006).

The ability to assess all five constructs was made easier with the development of a quantitative scale by a team of UK- and New Zealand-based researchers, (Weinman et al., 1996), the illness perception questionnaire (IPQ), which has over the past 25 years seen significant testing

attributions

a person's perceptions of what causes beliefs, feelings, behaviour and actions (based on attribution theory) and validation in a wide range of health conditions and populations across varying time-spans. The original IPQ which assessed the 5 dimensions above using 38 questions received significant support from a meta-analysis of 45 studies across 23 different health conditions, with evidence of construct and predictive validity including logical structure of the beliefs according to different illness characteristics, for example whether they were chronic or acute (Hagger and Orbell, 2003). (Meta-analysis of findings regarding causal attributions, given the range of conditions studied, was problematic.)

A child-specific version (CIPQ, Walker et al., 2006) was piloted among children aged 7–12 with asthma and eczema, and, although overall it performed satisfactorily, the cure–control scale did not show acceptable internal consistency, suggesting that perhaps children of this age did not fully understand the concept of personal control or potential for cure. Interestingly, this subscale had also performed less consistently in several adult studies and thus the control/cure items were a main target of IPQ revisions and seen in the subsequent version, the IPQ-R (Moss-Morris et al., 2002; Moss-Morris and Chalder, 2003).

The IPQ-R added new subscales to distinguish between beliefs about personal control over illness from outcome expectancies and from perceived treatment control; strengthens the timeline component by adding items regarding cyclical illnesses as well as acute/chronic timeline items; assesses a new dimension of emotional responses to illness such as fear and anxiety (this part of Leventhal's self-regulatory model not well addressed in the original IPQ) and finally, examines the extent to which a person feels they understand their condition, defined as illness coherence. Participants completing the IPQ-R are asked to rate the extent to which they agree or disagree (five anchor points of Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree) with the type of statements presented in Table 9.2, with one exception - identity is generated by a tick-list for a range of provided possible symptoms that the person believes are 'related to my illness'.

The IPQ-R (73 items) was initially tested across eight conditions but subsequently has also been tested for 'fit' among samples with rarer conditions (e.g. oesophageal cancer population, Dempster and McCorry, 2011; haemodialysis patients, Chilcot et al., 2010). Researchers should, however, seek to confirm the domains of IRs held in the populations, and illness they are themselves studying. The IPQ-R has also been tested in children: for example, in a small study of 15 children with juvenile idiopathic arthritis (Barsdorf et al., 2009), where it operated satisfactorily with the exception of Timeline Cyclical and one of the Treatment Control items, and where children under 12 needed more of the terms explained (e.g. permanent, hereditary, immune system). Young people with diabetes, both pre-adolescent and adolescent, were described as having 'a basic understanding of the nature, cause and timeline of their illness and treatment recommended' (Standiford et al. 1997, cited in Griva et al., 2000); however, there is now convincing evidence that children have similar multidimensional illness representations to adults, with perceived illness consequences and issues of control being highlighted in both quantitative and qualitative studies.

**Table 9.2** Examples of items assessing illness representations

| IR domain | Question example |
|---|---|
| Identity | Circle 'yes' or 'no' for any of the symptoms listed below that you think are related to your illness |
| Timeline | My illness will last for a long time |
| Consequences | My illness does not have much effect on my life |
| Treatment control | My treatment will be effective in curing my illness |
| Personal control | What I do will determine whether my illness gets better or worse |
| Illness coherence | My illness is a mystery to me |
| Possible illness cause(s) (18 listed, plus space to identify the three causes of the person's illness that they consider most important) | Stress or worry; Hereditary-it runs in the family; My own behaviour |
| Emotional representations | My illness makes me feel angry |

The Brief IPQ (Broadbent et al., 2006) was designed for more simple and rapid assessment, to facilitate for example use within clinical settings, intervention studies, or as part of a larger battery of measures. Using eight single items with one per IPQ-R dimension, but using 0–10 scaling of each response, plus offering space to identify the top three perceived causes, the Brief-IPQ has become very popular. Broadbent and colleagues (Broadbent et al., 2015) carried out a review of 188 papers which had used the B-IPQ between 2006 and 2013 across a wide range of illness types and age ranges across 36 countries and in 26 different languages. Many studies omit the causal attribution component, but in spite of that Broadbent concluded that the B-IPQ demonstrated good concurrent and predictive validity when examined in relation to various outcomes including anxiety, depression, indices of adherence and quality of life.

The existence of reasonably well-validated quantitative assessment tools, used in most of the studies described above, should not detract from the important contribution made by more open-ended methods of eliciting illness perceptions. For example, while we present evidence below supporting the associations specified in the common-sense model of illness, it could be said that they are limited in the extent to which they develop our understanding of what lies *within or behind* the representations presented. Understanding the sources and salience of beliefs and perceptions, and the reasons behind these, could be crucial to the development of targeted interventions. The value of qualitative enquiry can be highlighted by the findings of a study exploring cultural differences in illness perceptions regarding 'fatigue' between European American women and South Asian immigrant women (Karasz and McKinley, 2007). Using a case vignette of a woman suffering from fatigue, conceptions were elicited which revealed that, while some conceptions of fatigue were shared (e.g. perceiving both physical and psychological general causes), there were significant differences. For example, European Americans referred more often to genetic causes, medicalised/somatised the condition more and considered it a chronic condition, whereas South Asian women tended to think fatigue was temporary, caused by something transient and less needing of medical treatment. In exploring reasons for these differences, the qualitative accounts identify differing models of illness – a biomedical 'disease' model (European Americans), and a more socially oriented 'depletion' model (South Asians) that also drew on traditional 'humoral' concepts of illness (see Chapter 1 ☛). The similarities and differences between this study sample may not of course hold for other symptoms or for other comparison groups. Culture, these authors note, is more than simply a demographic variable, and more qualitative research is needed to explore 'the structures, contexts, conditions, ideologies, and processes through which culture shapes illness cognition and illness behaviour' (p. 614). Even this study however invited to respond to predetermined IR dimensions rather than allowing more spontaneous responses to the vignette scenario presented. Research allowing more spontaneous elicitation would help establish whether the IR dimensions outlined in the Common-Sense Model are actually implicit in peoples' models of illness. This can be illustrated from the findings of the following studies. The following quotes from cancer patients, one regarding cause and the other regarding consequences convey a depth of emotion what would be hard to capture quantitatively:

> . . . to begin with, it just didn't sink in that I was really sick. I had a lot of difficulty in grasping it, because . . . we have lived pretty – soundly I think . . . outdoors a lot. And that, that I have heart problems also. I just don't really understand that it has turned out like this . . . And just that one should exercise a lot and try to eat properly and I've done that, largely because you don't want to gain weight either, but no – I don't understand it.*(woman with lung cancer reflecting on the onset of her condition, Leveälahti et al., 2007: 468)*

> . . . I don't feel a proper man. I feel . . . completely emasculated and it's difficult to explain but I still have a problem wearing jeans. I still have a problem wearing shorts. Because I think that people know.*(man aged 48, diagnosed with penile cancer when aged 46; Branney et al., 2014: 411)*

Furthermore, our measures of illness perceptions (and in fact illness impact and outcomes) (see Chapters 14 and 15 ☛) tend to focus on the negatives, where we should acknowledge that illness perceptions can express hope also e.g. for a diagnosis that will lead to treatment and improved quality of life.

## Evidence supporting the 'common-sense model' and illness representations

Empirical findings have supported Leventhal's theory of *logical interrelationships* between component IRs: for example, strongly believing that an illness can be controlled or cured is likely to be associated with fewer perceived serious consequences of the illness and a short expected duration. Most studies using the IPQ-R, including those in non-Western populations (e.g. Chen et al., 2008; Hagger et al., 2017) have found that emotional representations are highly correlated with perceived consequences (high perceived negative consequences associated with high anxiety representation). The clustering and relationships between the component parts of an illness representation may be just as important in fact than the individual components, in that overall this reflects illness understanding (in addition to the IPQ-R's illness coherence subscale); however, few studies test this statistically. Most studies still tend to correlate the individual components with outcomes separately rather than evaluating the complex interactions between CSM components over time, as noted by Leventhal himself (Leventhal, Phillips and Burns, 2016). Chen's findings also highlight that cognitions and emotions are hard to disentangle causally, as acknowledged by Lazarus and colleagues in relation to stress-coping theory **(Chapter 11 ☛)**.

There is evidence also, that while the domains of IR hold true in many different groups, their *salience* can vary. For example, when the IRs of patients with either chronic fatigue syndrome (CFS) or Addison's disease (AD) (both chronic illnesses with common symptoms of fatigue and weakness, but with clearer treatment for AD) were compared, although within each disease group the illness perceptions were similarly interrelated, differences existed *between* illness groups: CFS patients viewed their illness more negatively than AD patients and reported more frequent and serious consequences and less positive future expectation of control or cure (Heijmans and de Ridder, 1998). Therefore, although IR components were robust in terms of how they related to each other, illnesses differed in the specific strengths of each component. In a similar vein, a confirmatory factor analysis of the IPQ-R completed by a large sample (N = 587) of oesophageal cancer patients found that the domains of the IPQ-R model 'fitted' the data adequately but that some of the questionnaire items, in particular those relating to timeline beliefs, needed further consideration (Dempster and McCorry, 2011). For example, one timeline factor was more closely aligned to the treatment control factor, suggesting that believing the illness will improve in time is, quite intuitively perhaps, related to treatment beliefs in this cancer sample. In addition, two acute/chronic items acted independently, suggesting that these patients can believe in both an acute illness model (it will last only a short time) but also in a chronic or permanent illness (i.e. perhaps something that will be with them till an imminent death). Such differences highlight the need for communications or interventions with patients to have specific focus, and not rely solely on generic observations drawn from other populations.

The content and organisation of IRs can vary between individuals and even within the same individual over time. Furthermore, one's own *health status* will affect one's beliefs regarding illness, and it should not be assumed that having an illness inevitably elicits more negative representations of that illness than those held by a healthy person. In fact the converse has been illustrated where perceptions of breast cancer and post-surgical treatment, mood and coping responses held by women who had received surgery for breast cancer were more positive than the perceptions and anticipated responses of healthy women, matched on age, marital status and educational attainment (Buick and Petrie, 2002). Healthy women overestimated the number, severity and frequency of patient symptoms (identity), rated patient health as poorer, believed more strongly in chance, internal (e.g. patient behaviour), genetic and environmental causes of breast cancer, believed that breast cancer had a longer timeline, that its consequences, including the emotional impact of treatment were worse and that treatment offered less cure or control potential. Healthy women also had more negative perceptions of how a woman with breast cancer would cope, thinking, for example, that patients would engage in generally avoidant coping such as venting emotion, using denial, alcohol, drugs or religion to a higher degree than patients themselves reported. The healthy women thought that patients were less likely to use positive reappraisal and acceptance coping, yet in reality these were the two most common strategies reported by patients. It is a sad fact that most people will encounter cancer at some point in their lives, either personally or through a family member or friend, and thus most of us have, to varying extents, a 'lay model' of this condition. Perceiving internal causes, or more specifically the person's behaviour, to be the cause of the illness may limit a healthy person's expression or provision of support for the ill person. Furthermore, if a societal perception of cancer is that patients' best cope by avoidance, then healthy members of that society may consider any attempts to discuss the illness with the affected person to be unhelpful. Mismatched perceptions have obvious implications in terms of responses to people with cancer (see Chapter 15 ☛), but they also hold implications for healthy individuals. For example, if the lay perception is that treatments offer little hope of cure, preventive health practices such as screening behaviour may be undermined. Therefore, identifying the illness

**Photo 9.3** Making screening accessible by means of mobile screening units in city centres may increase the likelihood of screening uptake.

*Source*: richardjohnson/Shutterstock.

perceptions of healthy individuals is highly relevant, not only due to their influences on their own behaviour but also as a means of increasing professionals' understanding of supportive behaviours towards those affected by illness.

## Culture and illness beliefs

Cultural differences have been reported in terms of other illness representation dimensions. For example, a study of perceptions of diabetes held by South Asians, Europeans and Pacific Islanders found that the Pacific Islanders perceived more symptoms of diabetes, greater consequences and were affected more emotionally by the condition than the other two groups, and that the Europeans differed from the other two groups only in terms of perceiving a longer timeline (Bean et al., 2007). The differences in beliefs identified related to poorer metabolic control and aspects of self-care, highlighting the importance of health professionals recognising individual's illness perceptions when trying to improve symptom or illness self-management.

Beliefs about treatment have also been shown to be influenced by culture, race and ethnicity in studies where comparison samples have been studied. For example, concerns about understanding treatments were higher among non-Caucasian cancer patients than Caucasian patients (Jean-Pierre et al., 2010), and African-American patients with end-stage kidney disease held more negative perceptions of illness control via either personal or medical treatments than Hispanic, Filipino or Korean patients (Kim et al., 2012). In this same study, while illness coherence beliefs did not differ between the groups, there were some gender differences seen within racial groups: for example, female Filipinos had lower personal control beliefs than male Filipinos, and female Hispanics and female Koreans both had lower illness coherence scores than their male counterparts. These, as in other samples in other cultures likely reflect socialisation processes.

While it is likely that cultural and religious factors will indirectly influence health and illness outcomes via their effects on health and illness beliefs and behaviours, longitudinal research evidence from cross- and within-culture comparisons is relatively limited, particularly within Western Europe. One study pointing to within-culture differences is that of Swami et al (2009), where Malaysian Muslim participants believed more strongly than Malaysian Buddhist or Malaysian Catholic participants that their likelihood of becoming ill was uncontrollable and that fate played a role in recovery. If pursued into a longitudinal study, such differences may well be reflected in different health behaviours (such as health-risk behaviours or seeking health care) and personal engagement in recovery from illness (cf. French et al., 2006).

## Illness perceptions, coping and outcomes

As described in Leventhal's self-regulation model of illness one likely route through which illness perceptions affect illness outcomes, both physical and emotional, is through their effect on coping responses, A person's perceptions of illness will 'make sense' to them and will influence what they do- how they cope. Dempster and colleagues (Dempster et al., 2015), in a review of 26 distinct studies of illness perceptions and coping across a variety of chronic health conditions found that, although illness perceptions typically explained between 25 and 30 per cent of the variance in health outcomes, of anxiety, depression and quality of life, coping was a stronger predictor than illness perceptions. Furthermore, contrary to what is proposed by the CSM, coping did not seem to mediate the effect of the illness perceptions.

While there has been meta-analytic support for the contribution of illness representations to coping and illness outcomes from early studies using this model, (Hagger and Orbell, 2003), the effects reported in more recent meta-analyses are often small and vary depending on the outcome addressed (e.g. Brandes and Mullan, 2014, in relation to adherence; Hudson et al., 2013 in relation to anxiety, depression and self-care in those with diabetes, Dempster et al., 2015, in relation to a range of outcomes and conditions; Hagger et al., 2017, also in relation to a range of outcomes and conditions). Generally speaking however, perceptions of high identity, chronic timeline, serious consequences and high emotional representations are associated with venting and avoidance coping, whereas perceived controllability (personal and treatment control) and illness coherence are more often associated with problem-focussed coping, reappraisal and support-seeking. Hagger and colleagues report significant and 'non-trivial' effects of IRs upon coping, the largest effect found being for emotional representations which positively predicted avoidance, emotional venting, and seeking support and negatively predicted problem-focussed generic coping and cognitive reappraisal.

In terms of outcomes, perceptions of high symptom identity, chronic timeline, serious consequences, and high emotional representations are typically associated with negative outcomes such as distress or lower physical, social or role functioning and not with adaptive outcomes such as wellbeing, whereas perceived control and coherence associate with better functioning and wellbeing. Direct and 'non-trivial' effects of perceived consequences and illness identity were in fact seen on all outcomes in Hagger et al.'s review (distress, wellbeing, disease state, functioning measures) (although the consequences-distress effect was small) (Hagger et al., 2017). However, even in this most recent meta-analyses many of the studies reviewed are **cross-sectional** and thus limited to providing evidence only of concurrent associations.

## Changes in illness perceptions

We have seen growth in the number of longitudinal studies conducted in this field which enables better testing of the CSM, which was always proposed to be a causal and dynamic model (Leventhal et al., 2016). For example, among head and neck cancer patients (Llewellyn et al., 2007) illness and treatment beliefs prior to treatment were *not* predictive of health-related Qol, generic QoL or mood, but they were associated with coping one month and six to eight months later. Chronic timeline beliefs held at baseline also directly predicted depression 6–8 months after treatment, i.e. the effect of the beliefs were not moderated by one-month coping strategies. In final

cross-sectional design

a study that collects data from a sample on one occasion only; ideally, the sample should be selected to be representative of the population under study.

## RESEARCH FOCUS

### Adhering to COVID-19 precautionary measures

Chong, Y.Y., Chien, W.T., Cheng H.Y. et al. (2020). The role of illness perceptions, coping and self-efficacy on adherence to precautionary measures for COVID-19. *International Journal of Environmental Research and Public Health*, 17:6540-6551

In a new pandemic, cross-sectional data can still bring interest – it can provide a snap-shot of experience at a critical timepoint, and it can direct attention to and provide insight into questions that might need further addressed in the future. The COVID-19 pandemic has brought with it a flurry of research; few health-related studies that I know of, that were ongoing at the time this virus emerged, have failed to incorporate some aspect of COVID-19 into their thinking. There has not yet been time to meta-analyse and synthesise the findings of the past 16 months. This study has been selected on the grounds of a) its relevance to the content of the chapter, b) because it took place at a very early stage in the pandemic and so will provide fruitful grounds for comparisons with later data, and c) it addresses behavioural adherence from the theoretical position of the self-regulation model of illness, and not from socio-cognitive models (as typically applied to behaviour) (see Chapter 5 ☛).

### Aims

This paper seeks to understand the role played by the factors identified in the CSM in precautionary behaviours around COVID-19 infection- that of illness perceptions and coping strategies. Further, in acknowledging the COM-B model of behaviour (see Chapters 5 and 6 ☛) where a person's capability to perform a given behaviour, is viewed as critical, they examine the additional influence of self-efficacy.

### Methods

As part of a larger online survey taking place in 78 countries (University of Cyprus, 2020), Chong et al. (2020) investigated illness perceptions held by 514 adult participants during the *second wave* of COVID-19 in Hong Kong (April–June 2020). This was a convenience sample of Hong Kong citizens recruited through social media, university email, and psychological associations (and thus does not claim to be representative).

In addition to sample demographics, data was gathered regarding:

- *individual's illness perceptions*: illness representations of consequences, timeline, illness concern and emotional representations (4 items from the Brief IPQ combined into one score), plus three belief items respectively addressing perceived susceptibility and perceived severity (as per the Health Belief Model) **(Chapter 5 ☛)** providing two subscale totals for analysis;
- *coping*: three dimensions were assessed- avoidance (five items), seeking social support (four items), problem-solving (two items, (from the Brief COPE) with items treated separately in analyses;
- *self-efficacy*: five items specifically addressing appraisal of one's competencies in planning and executing precautionary measures and treated separately in analyses;
- *adherence to precautionary measures*: three items each assessed on an 11point scale assessed the extent of adherence to physical distancing, limiting travel, washing hands. Combined into one score.

### Results

The recruited participants were predominantly female (74 per cent) and educated to a degree level or more (81.9 per cent), working in a non-healthcare profession (88.3 per cent). In addition, 98.6 per cent had to their knowledge not been infected by COVID-19. About a third reported staying at home and having worsened finances since lockdown measures were put in place. Correlational analyses revealed a significant relationship between more negative illness perceptions (representations and health beliefs), high self-efficacy, high problem-focussed and low avoidance coping and adherence to

*(continued)*

precautionary measures. Notably, illness representations and perceived severity were not consistently associated with the self-efficacy items, but perceived susceptibility was negatively associated with three of the five items.

Structural equation modelling (SEM) which adjusted for sociodemographic and lifestyle characteristics found both a significant direct relationship between illness perceptions and adherence and indirect effects of IRs via their effect on seeking support, problem focused and low avoidance coping. Only (low) avoidance coping had a significant relationship with adherence behaviours suggesting possible mediation of the effects of the illness perceptions on adherence. Also, in the SEM a significant negative relationship between illness perceptions (combined) and self-efficacy (combined) was evident, and as self-efficacy also had a significant pathway with adherence, self-efficacy would appear to mediate the effects of illness perceptions on adherence. The overall model explained 28 per cent of the variance in adherence to precautionary measures, which is significant, but leaves a lot of variance unexplained.

## Discussion

This study has some limitations, for example, the study is cross-sectional and sampling is opportunistic and biased towards educated females. The survey relied on self-report, had to be kept short and as a consequence full measures of illness perceptions and coping were not used. Furthermore the illness perception items were combined into one score making distinction of the salient components impossible. This could be important with regards to the pandemic context and the possible salience of emotions – we can not see for example whether emotional representations are more salient than beliefs around illness consequences. What we do see however is the importance of avoidance coping, itself typically associated with emotional representations and emotions such as anxiety. Future studies would do well to address the impact of emotions on health behaviours (and associated cognitions/perceptions) and given the media attention during this pandemic, emotions may have become even more salient than seen for other more ‘established’ conditions.

Limitations aside, this study points to an extended CSM, through its inclusion of perceived susceptibility and severity beliefs, and inclusion of a capability factor, self-efficacy. It also points to other concepts that may add further explanation to the model, that of perceived and actual social norms for example and the willingness to engage in ‘prosocial’ behaviour for the benefit of one’s community as well as for oneself. Since writing this ‘Research focus’ it is likely that studies addressing exactly these factors have taken place and so I would encourage you to do an up-to-date search of COVID-19 behavioural adherence studies.

When studies have taken a longitudinal approach and have addressed a more representative sample, then findings such as these, if replicated, would point to targets for public health interventions, i.e. with regards to reducing avoidance-based coping and increasing precautionary self-efficacy, and considering the role illness perceptions play in these relationships.

predictive analyses, coping and satisfaction with information received pretreatment were more predictive of these outcomes than IRs; however, the sample size prevented statistical tests of the effects of change in key variables over time. The fact that predictor variables may change over time and thus vary in the extent to which they predict outcomes is critical, as demonstrated in a six-year follow-up study of 241 osteoarthritis patients (Kaptein et al., 2010). In this study, those participants whose perceived illness timeline, personal control and illness coherence reduced over time or whose chronic timeline, identity, emotional representations and consequence beliefs increased (described as having a negative illness model) exhibited less positive pain and functional outcomes. Similarly, among a sample of informal caregivers assessed over a nine-month period, an increase in perceptions of illness consequence was predictive of caregiver anxiety and decreases in perceived control beliefs and increased emotional representations predicted caregiver depression (Parveen et al., 2014) and increased illness coherence predicted reported caregiver gains (Parveen and Morrison, 2012).

It is important to examine the interrelations between components and outcomes over a changing illness course, i.e. to explore the dynamic nature of Leventhal's model explored as he intended. Many factors will influence whether beliefs about an illness change over time. One important influence could be for example, changes in one's treatment regime, In two studies of kidney dialysis and transplant patients, either those with chronic or end-stage disease (Griva et al., 2012; Janssen et al., 2013) changes in IRs showed consistent association with outcomes either negatively or positively, even though the actual underlying condition remained the same and only the treatment modality changed. Another influence can be receiving positive feedback from (results of) ones' personal coping strategies including even the experience of being rehabilitated (Fischer et al., 2010). In Fischer's study of adults with COPD, timeline cyclical (not chronic) and personal control beliefs significantly increased between baseline and a follow-up assessment conducted within one month of completing rehabilitation. In both cases the stronger beliefs could be partially explained by baseline timeline or control beliefs but also by patient perceptions of having achieved their desired goals through taking part in the rehabilitation programme. In addition, beliefs changed in a coherent manner. For example, a reduced perception of illness consequences was associated with a reduced illness identity and a lowered emotional response; increased illness coherence was associated with a lowered emotional response, and increased perceptions of control were associated with increased belief in treatment control. These latter findings also relate to consistently found intuitive intercorrelations between the component IRs, as confirmed in a relatively recent meta-analyses of an impressive 254 studies relating to a sample size of 52, 599 study participants! (Hagger et al., 2017). Taken together, such findings highlight a need to consider patient's perceptions at important treatment transition points in order to best 'manage' their perceptions and optimise patient outcomes.

In the large meta-analyses of Hagger and colleagues we have also seen more complex statistical modelling which has better tested for the presence and effect of moderator variables. The studies in this field are very heterogenous (varied) in their findings of relationships between IRs, coping and outcomes and so it had been proposed that these differences may be due to the influence of moderating factors such as study design, illness type, illness stage, symptoms characteristics and the methodological quality of the studies (Hagger et al., 2017). In testing these moderators however Hagger found 'little indication of systematic variation in effect sizes attributable to the candidate moderators . . . ' (p. 1130) however they note that systematic comparison of all possible moderators within each individual study given its own sample characteristics, study design, measures and timepoints would be the ideal, and that their review simply was unable to do that. There are many, many, factors that influence beliefs, coping and outcomes, as you shall see in this and other chapters, we can only hope that better designed studies will consider more fully the moderators within their data and more fully test the CSM and all of its interacting components.

It may in fact be impossible to have a model or measure to fit all illnesses: for example, potential for cure or treatment simply does not exist for all conditions and in such cases this dimension would likely lack validity. In contrast, most illnesses bring with them some perception of 'cause', as we discuss next.

## Causal attributions

Attributional models are all about where a person locates the 'cause' of an event or, here, symptoms and/or illness. We make attributions in order to attempt to make unexpected events more understandable or to try and gain some sense of control – if we know 'why' something has happened, we can elicit and direct our coping efforts which should, ideally, help our adjustment (Park, 2010). Of course, attributions can be wrong and thus coping efforts misguided, as we will see. The majority of attributional research in health psychology has addressed 'ill populations', such as those who have suffered a heart attack (myocardial infarction) or heart failure (e.g. Gudmunsdsdottir et al., 2001; Timmermans et al., 2018), or those with cancer (Costanzo et al., 2011; Salander, 2007; Gall and Bilodeau, 2017). In relation to heart attack, attributions of cause – stress, work, it being in the family, smoking, eating fatty foods can be recorded either spontaneously (patients asked to describe what they think about their illness), elicited (asked directly about their ideas of what may have caused their heart attack) or cued (asked to respond 'yes', 'no' or 'might have' to a list of 34 causes) (e.g. Gudmundsdottir et al., 2001). In a study of 595 European heart failure patients (Timmermans et al., 2018) asked to report what they perceived the cause of their heart failure was, using the open-ended final question of the Brief IPQ (see earlier), 11 per cent offered no causal explanation, 46 per cent offered a physical cause, typically other comorbidities, 38 per cent offered a behavioural cause, mainly their smoking; 35 per cent offered a psychosocial cause, mainly work-place stress, and 32 per cent cited natural causes such as their genetics. As you can see this adds up to more than 100 per cent, reflecting the fact that individual can state multiple causes, some of which are external attributions reflecting a form of self-preservation bias (French et al., 2001). This bias was also reported in a rare longitudinal study of lung cancer patients (Salander, 2007). It is a relatively well-established fact that smoking accounts for about 80 per cent of the incidence of lung cancer (Chapter 3 ☛), yet among the 16 smokers interviewed repeatedly (of a sample of 23), the two most common attributions of 'cause of their illness' was 'don't know' and 'environmental toxins/pollution'. A total of 14 did not consider smoking as a probable cause, and the author points to this as a defence mechanism or 'disavowal', potentially useful for a sample at a relatively late stage in their illness. Another disease with a strong association to smoking is COPD (chronic obstructive pulmonary disease) and, in contrast to Salander's study of lung cancer patients, the vast majority of this sample (93 per cent of 394 patients with a smoking history) agreed or strongly agreed with smoking as a cause, with workplace/environmental pollution, and infection/pneumonia also common (48.5 and 36.5 per cent respectively).

These patients, however, were not newly diagnosed (Hoth et al., 2011). When attributions are examined at an earlier stage in illness experience, i.e. at the time of symptom perception, the dimensions of controllability, locus (internal physical/external non-physical cause) and stability described by attributional theorist Weiner (1986) which have been consistently reported in studies of illness attribution and coping (Roesch and Weiner, 2001), are less commonly reported. At symptom onset it is more common to attribute bodily signs or symptoms to either a physical (e.g. age, exertion)–non-physical (e.g. stress, mood) dimension; a high–low personal controllability dimension; and a dimension thought to reflect controllability by health professional/treatable versus stability/not treatable. Attributions of the causes of symptoms (rather than attributions of cause of a confirmed illness) may be an area worth further exploration, given cultural and other influences thereon (see below). Perceiving a cause of fatigue as being physical, under high personal control and stable/not treatable may lead to very different interpretation, response and health-care-seeking behaviour than a cause of fatigue with external, supernatural attribution.

Typically, when unexpected or undesirable things happen to us, we look for an explanation or explanations. Understanding 'why' something has happened can help us act in a way to prevent it happening again, or help us manage or adjust to any changes the event brings with it. As described above, causal attributions can be internal or external, specific or global, and stable (uncontrollable) or unstable (potentially controllable). A less commonly studied perceived external cause of illness or initial symptoms includes spiritual and the supernatural (to God, (God's Will, God's Punishment, God's Anger (Gall and Bilodeau, 2017), the evil eye, hexes, other spiritual beliefs, to Fate or Destiny) although these causes are under researched and even where they are assessed they are commonly not reported in Western samples (Vaughn et al., 2009).

Attributions of cause can be affected by one's own illness experience and can potentially affect how we respond to illness in others; they can also influence how we respond to our own illness: for example, perceiving diet as a causal factor in breast cancer increases the likelihood of dietary change following treatment (Costanzo et al., 2011). Unfortunately however, they can sometimes be wrong. For example, a woman may attribute joint pain to excessively high-heeled shoes rather than to the first signs of arthritis, and she may fail to seek medical advice. Other risks of misattributed cause is failure to adhere to essential medication: for example, a study of women with HIV infection found that drug treatment was wrongly attributed as causing their symptoms, leading to reductions in, or cessation of, medication adherence (Siegel and Gorey, 1997).

It has been suggested that the medical sociological tradition of assessing lay models of health and illness (e.g. Blaxter's study – see Chapter 1 ☛) – which takes a broader view of beliefs and knowledge shaped by social factors such as social class, culture or economic environment – and the health psychological model of individual cognitions (illness perceptions, as described in earlier sections) should be merged. An example of this can be seen in studies examining cultural variations in illness beliefs. Culture influences illness at many levels in that it shapes both how it is perceived, understood and experienced (Adams and Salter, 2009). For example, as described above (and in Chapter 1 ☛) there is significant variation in the extent to which members of specific cultures believe in supernatural causes of illness: e.g. evil spirits, divine punishment or in spiritual explanations (Vaughn et al., 2009). In terms of the latter, it has been described how Chinese women made sense of their cancer experiences by attributing their cancer to '*tien ming*' (the will of Heaven, a concept from the Chinese Confucian and Daoist traditions) and to 'karma' (a Buddhist concept of cause and effect that cannot be changed through human effort) and as a result showed acceptance and 'going with the flow' ('*ping chang xin*') (Leung et al., 2007).

## Planning and taking action: responding to symptoms

The first step towards seeking medical care begins with a person recognising that they have symptoms of an illness, and, as described in this chapter there are many influences on this step. In many cases, people choose to treat an illness themselves by self-medicating, others will wait to see whether they recover naturally, go to bed and await recovery, or consult with a friend (see below). The percentage of people who report their symptoms to a health professional ranges from as low as 5 to only 25 per cent (e.g Elnegaard et al., 2015).

Kasl and Cobb (1966a) refer to the behaviour of those who are experiencing symptoms but who have not yet sought medical advice and received a diagnosis as **illness behaviour**. Illness behaviour includes lying down and resting, self-medication and seeking sympathy, support and informal advice in an attempt to determine one's health status. Many people are reluctant to go to the doctor on the initial experience of a symptom and instead first seek advice from a **lay referral system**, generally including friends, relatives or colleagues (Croyle and Barger, 1993). Symptoms are therefore not always sufficient to motivate a visit to the doctor (see ISSUES) and the recognition that one has symptoms is also insufficient for deciding that one is 'sick' (Radley (1994: 71). Think of your own experience – symptoms do not necessarily precede 'sickness' – sometimes only by virtue of receiving a diagnosis of sickness will one adopt what is termed **sick role behaviour** (Parsons, 1951; Kasl and Cobb, 1966b).

Once people recognise a set of symptoms, label them and realise that they could indicate a medical problem, they therefore have the option of:

- ignoring the symptoms and hoping they recede;
- seeking advice from others;
- presenting themselves to a health professional.

Some people will do all three over time.

Our response even to serious symptoms may still involve some delay to see whether things improve or whether attempts at self-care will improve the situation. A dramatic example of this was reported by Kentsch et al. (2002), who found that over 40 per cent of patients who thought they were having a heart attack, *and who considered this to be potentially fatal*, waited over one hour before calling for medical help. This delay would have had a significant impact on the outcome of their illness. Treatment with 'clot-busting' drugs, which dissolve the clot that causes an MI and minimise damage to the heart, are at their most effective when given within an hour of the onset of problems. Cockburn et al. (2003) also found significant evidence of our ability to ignore unusual and potentially important symptoms. In a survey of over a thousand adults, they found that 23 per cent of their sample reported having had blood in their stools (a potential symptom of bowel cancer) – but only one-third had ever reported these symptoms to a doctor. Perhaps more encouraging was the reporting of breast

**illness behaviour**

characterises a person who is sick and who seeks a remedy, e.g. taking medication; usually precedes formal diagnosis, when behaviour is described as sick role behaviour

**lay referral system**

an informal network of individuals (e.g. friends, family, colleagues) turned to for advice or information about symptoms and other health-related matters; often (but not only) used before seeking a formal medical opinion

**sick role behaviour**

the activities undertaken by a person diagnosed as sick in order to try to get well

## ISSUES

### Where do you go to with your symptoms?

It is estimated that approximately 60 per cent of internet users will use the internet for health-related purposes (particularly younger populations and those with chronic disease), primarily seeking information about a condition or a treatment using health-professional sites, but also to read health-related patient blogs, join patient forums or access other social media in healthcare (Thackeray et al., 2013; Rueger, Dolfsma and Aalbers, 2021).

When something doesn't 'feel right' but we are unsure as to whether or not the bodily sign is symptomatic of something worthy of making an appointment at a doctor's for, we may seek out symptom checkers online, many of which are offered by national health organisations (see for example in the UK https://www.nhs.uk/symptom-checker, Australia www.healthdirect.gov.au/symptom-checker), the Netherlands http://www.gezondheidsplein.nl/symptomenchecker/, Germany http://www.netdoktor.de/service/symptom-checker/).

However while symptom checker websites such as these have become more sophisticated and gather information about your age, body mass, risk factors, etc. first, before asking what symptoms you are currently experiencing and making a tentative diagnosis, many less informed sites do not, and instead just take your symptoms and then present you with a long list of alternative diagnoses, from the mildly inconvenient to the life threatening! Symptom checkers carry risks of being misinformed – relaxing when one should not; over-reacting when one should not – but they do provide an extension to what is known as our 'lay referral system' (see below) and therefore should be treated as a modern extension to information sources people will likely use when first detecting a symptom.

More typically once an illness is confirmed many use online forums and various forms of social media to compare experiences with that of similar others. For example, at healthtalkonline.org interviews with a wide range of people about their health and illness experiences are shared in a series of over 70 modules that are underpinned by rigorous qualitative research. This website has attained registration with the Information Standard (UK) and is increasingly recognised as a useful educational resource, not just for patients and their families but also for students in healthcare, and health psychology! Recently, an impressive analysis of 12 years' worth of interactions (from over 108,000 users) within a large online Q&A health community highlighted that while not all advice received is considered helpful, advice from those with similar illness experience and who have had their advice endorsed as helpful by other users was the most valued (Rueger et al., 2021). However, some advice from others with similar conditions (but not necessarily the same characteristics or context) can also increase anxiety and confusion about what to expect from one's illness (Coulson, 2013). While peer interactions in online support communities, for example in the context of cancer, have been found to offer a low level of inaccuracies, they are not of course tailored to an individual's specific situation and needs (Gage-Bouchard et al., 2018).

The world of social media and access to online resources (not just in health) is expanding, with inherent risks as well as potential benefits. We still do not have great understanding of the role such health-relevant resources play in patient decision-making regarding health-care-seeking behaviour although studies such as those referred to above are addressing this knowledge gap. It is also plausible that the growth of online health-information-seeking behaviour and in mobile technologies more generally, has contributed to the increased use of electronically delivered interventions: for example, the use of text messages to prompt behaviour change (see meta-analysis by Head et al., 2013) or even Facebook (these intervention methods are discussed in Chapter 7 (☛). The norm of face-to-face healthcare is perhaps being challenged by new innovations, and possibly also by experiences during the COVID-19 pandemic where consultations moved online. Certainly for those who live geographically more remotely, online support care could have some advantages with regards to accessibility. Time shall tell whether our healthcare systems change.

## WHAT DO YOU THINK?

Health is one of our most precious attributes. Yet many people who fear they have an illness – in some cases one they think may be fatal – delay in seeking medical help. Interestingly, people who are in the presence of someone else when their symptoms occur are more likely to call for help than people who are alone at the time. It seems that by talking with this person they are given 'permission' to call for medical aid. Why should this be necessary? Think of your own illness experience and consider what you do when experiencing symptoms and whether you seek validation by others before seeking help. Factors influencing delay are discussed next.

lumps by women in a study by Meechan et al. (2002). They found that of their sample of women who identified breast lumps following breast self-examination, 40 per cent had seen their doctor within seven days, 52 per cent within fourteen days, 69 per cent within thirty days, and only 14 per cent had waited over ninety days. However, it should be noted that even among this group of health-aware women who took active steps to identify and prevent disease, a significant proportion still delayed significantly in reporting their symptoms to their doctor.

## Delay behaviour

Anderson (1995) describes a general model of patient delay behaviour, that examines factors influencing delay time between recognising a symptom and seeking help for it, and between receiving a healthcare appointment and receiving treatment. They described three decision-making stages at the individual level, and two which lie more at a system level (see Figure 9.5). In health psychology, we have been more concerned with delay behaviour in terms of the individual's delay in seeking health advice as opposed to delays inherent in the health-care system itself as these stages offer greater intervention potential. In many conditions, including cancer and heart attack, for example, delay in presenting symptoms for medical attention is highly related to outcomes of *morbidity* and mortality (e.g. Gibson et al., 2004; Henriksson et al., 2011), and thus it is important to gain an understanding of the factors that influence delay behaviour. Anderson's model has been tested in a range of conditions, including cancer (e.g. Walter et al., 2012). Illustrating the three levels of delay more under the individual's control are:

1. In the first stage, a person infers that they are ill on the basis of perceiving a symptom or symptoms – the delay in reaching this decision is termed 'appraisal delay' and is subject to all the factors described earlier in the Symptom Perception sections. Let us imagine that on Sunday you wake up with a sore throat (recognise symptoms); by Tuesday you decide you are ill (appraisal delay);
2. Next, the person considers whether or not they think their symptoms need medical attention and this will be influenced by personal, emotional, cognitive and social factors as we have described. The time taken to decide this is termed 'illness delay'. On Wednesday you decide to see your doctor;
3. The final stage covers the time taken between deciding one needs medical attention and actually acting on that decision by making an appointment or presenting to a hospital. This is termed 'behavioural delay', thus on Friday when the symptoms are still there you actually make an appointment to see the doctor (utilisation delay).

The third delay can extend into a fourth delay, known as a 'scheduling delay' reflecting the time taken between calling to make the appointment and actually getting seen – this is not typically under the individual's control. The final delay is in terms of when any treatment can be obtained or commenced and may be partly back in the individual's control, for example if it involves them picking up a prescription and then actually starting to take the medicine. The length of each delay period is likely to vary for different symptoms and illnesses, with, for example, appraisal delays being long for embarrassing personal symptoms such as rectal bleeding but for such symptoms scheduling delays are likely to be short. Appraisals are crucial in getting the help-seeking process moving along, particularly when symptoms are potentially lethal.

Recognising the importance of individual appraisal and recognising that the indiviudal's pathway to treatment is not necessarily a linear process as Anderson's model suggests, Scott et al. (2013) present a fuller model of patient delay built around psychological theory, including Social Cognitive theory and the Common Sense Model described in this chapter, (see Figure 9.6). By recognising more fully the social, healthcare system and contextual factors that coexist with patient-level factors such as

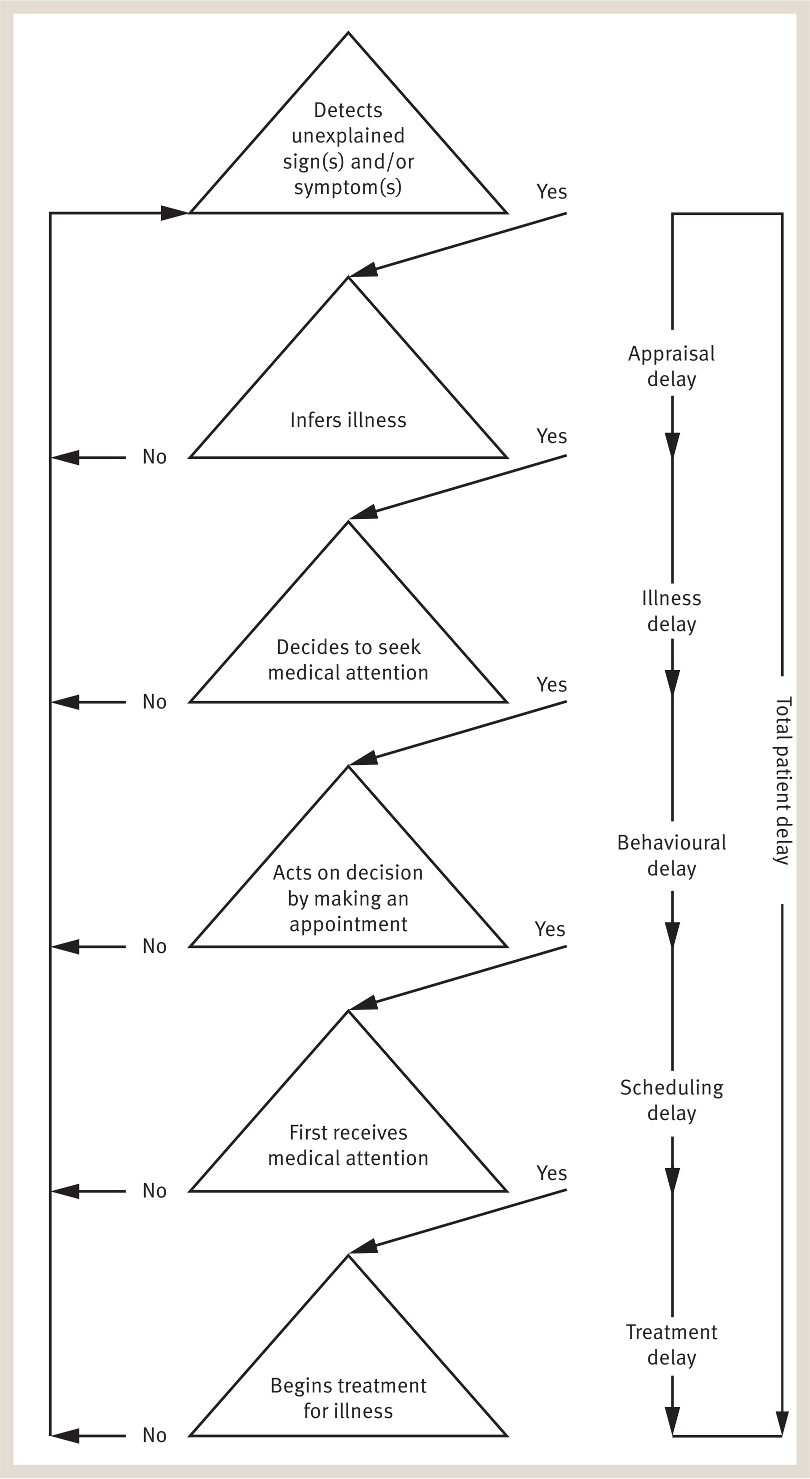


**Figure 9.5** A general model of patient delay

*Source*: Anderson (1995).

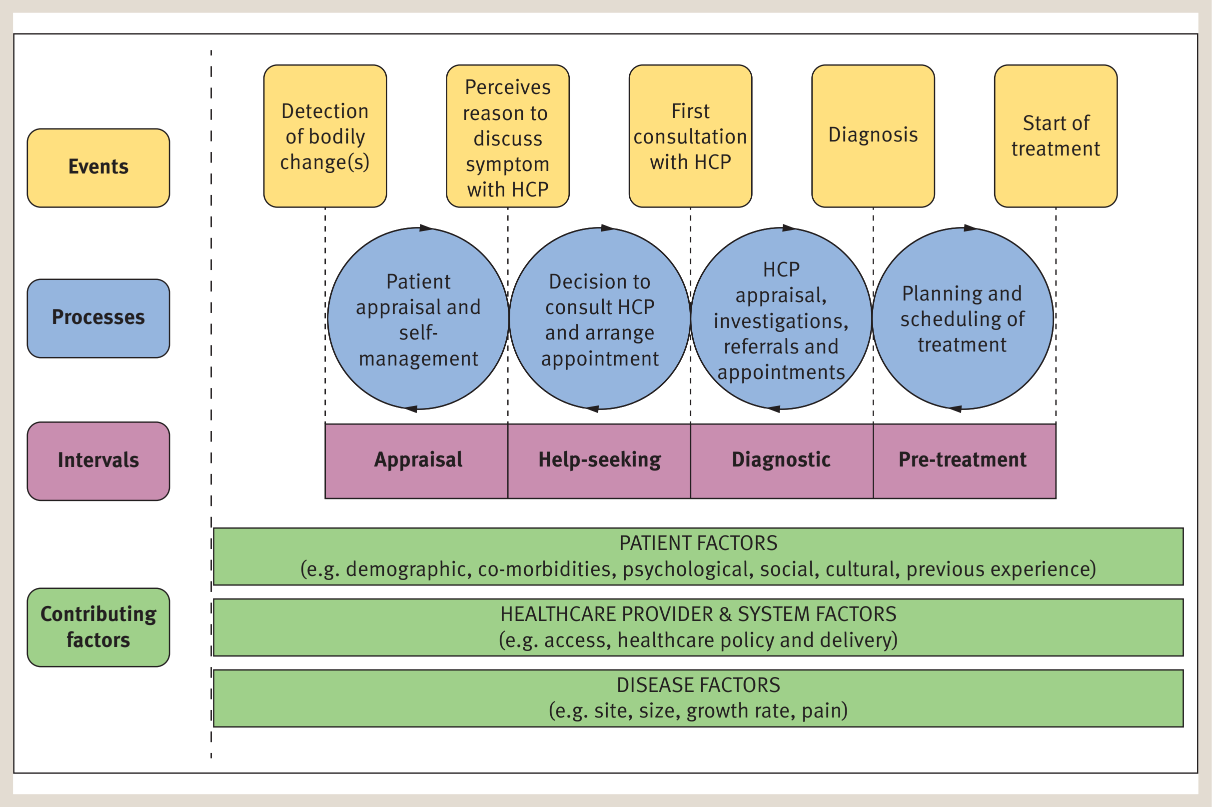


**Figure 9.6** Model of pathways to treatment

*Source*: Scott et al., 2013.

those presented in this chapter, this Pathways to Treatment Model portrays the complexity of healthcare seeking behaviour.

Many factors influence whether a person will or will not seek medical help above and beyond the symptom characteristics, socio-economics (the lower one's level of education and income, the greater the delay), or demographic characteristics (age, gender) (see Chapter 2 ☛), as described earlier. Hall et al. (2015) mapped out psychosocial factors (knowledge, beliefs, illness schemas, emotion, and coping) and social factors, particularly in relation to who the participants discussed their symptoms with others (lay referral). Personal beliefs about illness, treatments and expectations of health care and healthcare professionals interact with a range of emotional factors, and external influences such as social network behaviours. Table 9.3 summarises common practical, emotional and social reasons for seeking or not seeking medical attention, drawing from a range of studies across a range of conditions (including, for example Cheng, 2000; Lawson et al., 2007; Hale et al., 2010; Henriksson et al., 2011).

## Symptom characteristics

As described in the symptom perception section, symptoms that are visible, painful, disruptive, frequent and persistent generally (not always) lead to action. If the symptom is easily visible to oneself and others, for example a rash, then one will delay less in seeking treatment. When people believe that their symptoms are serious (whether or not subsequently confirmed by the doctor), unusual (e.g. no one else seems to have had them) and that they can be controlled or treated through medical intervention, they are more likely to take action. The

**Table 9.3** Reasons for seeking, delaying in or not seeking a medical consultation

| Reason |
|---|
| **Seekers** |
| Believe their symptom to be serious |
| Are experiencing life disruption as a result of their symptoms |
| Want information about symptoms and their cause |
| Want reassurance about symptoms |
| Want legitimisation of their concerns |
| Believe there is a treatment with the potential to manage or cure symptoms |
| Were encouraged to attend by a loved one or lay referral |
| Want to avoid the risk of symptoms progressing or things ‘getting worse’ |
| **Delayers or non-seekers** |
| Think they do not have time |
| Do not want to take sick leave from work or family responsibilities |
| Do not like clinics or hospital settings/ Do not trust the medical profession |
| Are worried about possible costs of treatment |
| Think the symptoms are ‘just a bug going round’, i.e. transient |
| Think the symptoms are not serious enough, i.e. are afraid of being ‘a nuisance’ or wasting doctor’s time |
| Are unaware of the potential meaning of their symptoms |
| Are reassured by friends/lay referral that their symptoms are not a cause for concern |
| Hold non-medical views of illness experience (see cultural influences below) |
| Are worried about appearing ‘weak’ (particularly in males) |
| Believe there is nothing that can be done, no treatment potential |
| Are worried or scared of the result and implications |
| Are fearful of possible tests and examinations |
| Are afraid of being judged negatively by the health-care professional for some behaviour they believe is associated with their symptoms (e.g. smoking) |

location of the symptom may also influence whether it is discussed with friends or family, for example headaches compared to rectal bleeding; and whether the person seeks professional advice or not- – certain parts of the body seem more open to discussion than others. The attributes and expectancies associated with some diseases may also influence ease of reporting; Hale et al. (2007), for example, noted that shame or embarrassment about the likely need for rectal examinations contributed significantly to delayed reporting of symptoms subsequently found to be associated with prostate cancer. This is also one of the reasons that many testicular cancers are diagnosed late, with potentially serious consequences (for cancer screening issues, see Chapter 4 (☛).

The effects of symptoms are also important. When symptoms threaten normal relations with friends and family, or when they disrupt regular activity or interaction, people usually seek help (Scott et al., 2013; Elnegaard et al., 2017). However, Grunfeld and colleagues (2003) found that even when a potential symptom of breast cancer had been self-identified, a significant number of women aged 35–54 delayed seeking health care in the belief that seeking help and potentially entering protracted treatment would be disruptive to their lifestyle!

Not seeking help for such symptoms could result in an illness and treatment regime significantly more disruptive than presenting to health care early.

Furthermore, people make judgements about the prevalence of symptoms and disease that influence their interpretation about whether they should seek medical attention. Diseases that a person has experience of have been found to be judged as more prevalent by both patients *and* by physicians, and diseases considered prevalent tend to become normalised and viewed as less serious or life-threatening. Thankfully, however, it has been shown that presenting with symptoms of a condition that one reports a family history for predisposes the emergency services to respond in an urgent manner.

### Financial reasons for delay

For some, seeking refuge in the sick role following a formal diagnosis might be an attractive option as it can allow a person time out from normal duties and responsibilities. However, some people do not want to be declared sick because of the implications it may have for them socially ('If I am sick how can I attend that party?'); occupationally ('If I am off sick my work will pile up and await my return or will someone else get my job?'); or financially ('I cannot afford to lose wages or overtime payments by being sick.' 'I cannot afford to pay for tests or medicines'). In the USA, some people delay seeking medical care when money for the anticipated treatment is limited; or where they do not have sufficient health insurance, although even when people have medical insurance, delay is present, for example, following a heart attack (Rahimi et al., 2007) (see Chapter 2 ☛). Treatment cost concerns are particularly highlighted within some minority groupings: for example, one American focus group study found that African-Americans were more likely than White or Hispanic American participants to report delaying calls to emergency services out of concerns about the costs and location of care (Finnegan et al., 2000). Luckily, many countries have health-care systems that make personal finance less of a barrier to treatment, for example the National Health Service in the UK.

## Cultural influences on delay behaviour

As described in Chapter 1 ☛ and also earlier in this chapter, there are cultural variations in perceptions of health and illness and these can differentially effect the health-seeking behaviours that follow. In some cultures beliefs distinguished between the use of traditional, complementary, alternative or Westernised healthcare, i.e. when multiple health-care systems operate in parallel in a society, they are used differentially depending on the specific illness and illness perceptions (Lim and Bishop, 2000; James et al., 2018). In many cases, individuals will seek culturally relevant cures, including, for example, herbal or animal-based treatments, acupuncture, indigenous practices such as faith healing, traditional bone-setting (e.g. in Sub-Saharan Africa), and so on. Complementary or alternative remedies can also be imported, e.g. Chinese medicines. In some cases, this may be associated with a parallel seeking of medical help – in others, seeking Westernised medical treatment may be considered only if the condition fails to respond to the more traditional remedies (Lim and Bishop, 2000; James et al., 2018). Delays in seeking professional medical help may in part result from holding specific cultural beliefs about illness causation that do not 'fit' biomedical views of illness and treatment (Mir and Tovey, 2002) but is also attributed to perceptions of traditional or alternative remedies being of lower cost, more natural or effective, although these perceptions may not be based on evidence (James et al., 2018).

Minority status, which includes ethnicity, but also gender, sexuality, lower levels of health literacy and so forth, may also contribute to delayed help-seeking where health-care consultations are seen as holding potential for humiliation or discrimination (Wamala et al., 2007). Delay has also been associated with fear of disclosure of symptoms out of fear of stigmatisation or social rejection due to the perceived burden of caring for a person with cancer (Grischow et al., 2018), as seen for example among Ghanaian women diagnosed with advanced breast cancer who had delayed presentation (Bonsu and Ncama, 2019).

Further discussion of the influence of ethnicity on health-care-seeking behaviour, and access to services, is covered in Chapter 2 ☛.

## Age and delay behaviour

Elderly people generally present to their doctors more quickly regardless of symptom severity and in spite of the fact that many symptoms are commonly attributed initially to ageing. The quicker presentation of older

**Photo 9.4** Communicating to children about their symptoms presents additional challenges

*Source*: DC Studio/Shutterstock.

individuals to health-care professionals has been interpreted as a need to remove uncertainty, whereas middle-aged individuals may attempt to minimise their problems, often relying on self-medication, until they worsen or fail to disappear naturally (Leventhal and Diefenbach, 1991). In terms of a symptomatic child, the responsibility for acting on, interpreting symptoms and subsequently seeking health care (or not) lies often with the parent or guardian, and it may be expected that delay would be minimal. However, this is not inevitable, and presenting a child to health care may be subject to similar influences as presenting oneself. For example, a Nepalese study found that, even when presenting a child to health care, the speed of seeking health care depended on maternal educational level, family income, and the number and perceived severity of symptoms (Sreeramareddy et al., 2006). In late adolescence the decision to attend moves away from some parents and these young people can become reluctant to seek medical attention, particularly if their symptoms are something they wish to conceal from their parents. For example Meyer-Weitz et al. (2000) interviewed 292 South African adolescent and young adults (aged under 20 years) about the influences on their seeking health care for a sexually transmitted disease. The majority presented within six days of symptoms (56 per cent), 23 per cent waited seven to ten days, and 21 per cent waited more than ten days. The reasons given by those seeking health care early were perceived seriousness of the symptoms, absence of any self-treatments and positive attitudes to autonomy and, perhaps surprisingly, to condoms. Adolescents may also delay in seeking health care out of a sense of invulnerability and a resulting optimism about susceptibility to health problems (see Chapter 3 ☛).

## Gender and delay behaviour

Women generally use health services more than men and we have already considered whether this may reflect greater attention being paid to internal states and bodily signals or gender socialisation. Perhaps women make better use of their social support and lay referral networks, which promote health-care-seeking behaviour (Krantz and Orth, 2000). However, the interaction between gender, socio-economic status, social support and health-care use is not yet fully understood (see Chapter 2 ☛) and any explanation is likely to be multifaceted, given the range of potential influences described in this section.

Gender differences in seeking medical help may occur as a result of different meanings given to health-related behaviour by the two sexes (Courtenay, 2000). The differences, they propose, and as reflected on at the start of this chapter, reflect issues of masculinity, femininity and power. Men show their masculinity and power by engaging in health-risking behaviour, by presenting late in the course of illness to add to a notion of not fussing or not malingering, and by not showing signs of weakness – even when ill. This has even been recognised by GPs where in one study they attributed the lower self-referral rate among men to their need to be seen as 'brave and manly', particularly in those of lower socio-economic status (Hale et al., 2010). A key explanation for men's poorer longevity (see Chapter 1 ☛) is likely to be their lower rate of usage of health services, including seeing their local GP or taking up opportunities for routine health screening (including dental and eyesight checks). Confirming this, a systematic review of 41 studies of factors associated with delays in seeking both medical and psychological help among men, found that being disinclined to express concern about their health or emotional state, embarrassment about their symptoms (seen for example in prostate cancer studies e.g. Medina-Perucha et al., 2017), anxiety and fear were the most common barriers to help-seeking. In addition, poor (past) communication with healthcare professionals was highlighted as a barrier to seeking help in the future, which points to the need for health care practices to be welcoming, supportive and accessible to all.

Women, conversely, are more willing to confront the implications of symptoms than men, for themselves, but also in encouraging their male partners as seen in the context of testicular, bowel and prostate cancer, for example, where women are often highly influential in encouraging their male partners to attend for doctor consultations (e.g. Hale et al., 2007). It is also reported that by presenting because 'someone else said I should come' men can preserve their masculine image as someone who 'doesn't fuss about his health' (Hale et al., 2010).

Finally, there may be preferences in who we see when we go to a GP. Previously it has been shown that both male and female patients prefer to see female GPs when presenting with 'personal' or 'sexual' problems, although the evidence is inconsistent. It is speculated that female doctors are more empathic and reassuring in their communications with male patients than male doctors, consistent with gender differences in health-care professional communications (see Chapter 10 ☛). Findings from Hale's interview study suggested that male doctors may be unsympathetic to a regularly presenting male patient, however further research needs to compare these attitudes with those held by female GPs who may also judge male patients differently to female patients. Both male and female GPs may make judgements about who over-attends and certainly inappropriate attendance is a challenge to medical services whatever the gender of the patient or GP. It is also important to know whether patients' perceptions of critical judgements being made of them by GPs is borne out, as the GP is our first line of approach for many critical screening and treatment services. Are GPs ambivalent to the self-referrals of certain types of patient? If so, does it affect any aspects of their communication or treatment actions? These issues are controversial, but nonetheless need to be addressed.

## Influence of others on delay behaviour

At times discussion of symptoms with other lay persons can normalise a participants' symptoms and create a delay in terms of gaining healthcare advice, as seen in a qualitative study of 40 participants referred to healthcare on the basis of colorectal symptoms, 18 of whom subsequently received a diagnosis of colorectal cancer (Hall et al., 2015). People often take action only when they are encouraged to do so by others in their lay referral network or when they realise that others with the same problem sought help in the past. It appears that many people look for 'permission' to call for help from their friends or family members – and are more reluctant to call for help in its absence (Kentsch et al., 2002; Henriksson et al., 2011). Related to this are delays as a result of 'not wanting to bother anybody' or a desire to protect one's loved one's (Forbat et al., 2013). However discussing symptoms with others can be helpful, consider for example mentioning a symptom to your parent and discovering that it reflected a family history that warranted medical check-up (Weinman and Petrie, 1997). Disclosures of family history or of others' illness experiences are a likely outcome of conversations within a lay referral network, however, not all social networks are helpful: some people consulted may distrust doctors after negative experiences of their own; others may believe in alternative treatment or therapies rather than traditional medical routes; yet others may decide that the symptoms reflect something else going on, their friend/relative being stressed for example. The use of lay referral networks, including online networks (see 'Issues') can therefore work for or against delays in the seeking of health care.

## Treatment beliefs and delay behaviour

In an extension to Leventhal's self-regulation model (described earlier) Horne and colleagues (Horne, 1999; Horne and Weinman, 1999, 2002) identified treatment representations whereby medicines are perceived as restorative, as symptom relievers, or as disruptive, harmful or addictive. Believing that one has a serious illness but that it can be cured with a relatively straightforward treatment was considered to be more likely to result in seeking medical help than where the opposite cluster of beliefs existed. Beliefs about treatment come from various sources (past experience of self or others, online searches – see 'Issues') and they may also influence decisions to seek or not seek health-professional advice for a symptom. For example, among patients with type 1 diabetes, perceived treatment effectiveness was a significant predictor of attendance at health-care clinics along with the coping strategy of seeking instrumental support (Lawson et al., 2007).

Perhaps due to growing concerns about some traditional medical treatments (e.g. antibiotics, steroids, HRT – hormone replacement therapy), Western populations are increasingly turning to complementary therapies, involving both physical and non-traditional pharmaceutical interventions, such as acupuncture, chiropractice, homeopathy and alternative therapies such as traditional Chinese herbal medicine or Indian Ayurvedic medicine (Vaughn et al., 2009; James et al., 2018).

## Emotional traits, states, and delay behaviour

As described in the Perception and Interpretation section, Neurotics and those high in trait NA are more likely to report symptoms however, there is a more limited literature examining the influence of such personality traits on health-care-seeking behaviour (Williams, 2006). Neurotic individuals, tend to over-attend to internal bodily signs and over-interpret and over-report symptoms; this means that they generally exhibit shorter delays in seeking help than those less neurotic individuals (O'Carroll et al., 2001). However, it has been suggested that their consulting style, of elaborate symptom description, for example, works against them being seen as credible and potentially undermines the medical care they receive (Ellington and Wiebe, 1999).

In terms of emotional states, fear and anxiety have been inconsistently associated with delay in seeking health care. O'Carroll et al. (2001), for example, found that people who had relatively high scores on a measure of dispositional anxiety were more likely to seek help quickly following the onset of symptoms than their less anxious counterparts. Delay in seeking medical care was however not significantly associated with anxiety among a study of individuals with head and neck cancer (Tromp et al., 2004). In relation to a range of symptoms assessed in a large Danish survey, Elnegaard and colleagues (Elnegaard et al., 2017) found that worry about symptoms was more associated with help-seeking in younger participants (20–39-year-olds) than in older age groups (40–59 years; 60–79 years, over 80 years). While fear of doctors, treatment procedures or medical environments can delay healthcare-seeking, and trait anxiety, neuroticism and negative affectivity are generally found to increase non-emergency health-care utilisation, illness-specific anxiety appears to be less influential. A meta-analysis of studies examining the prospective relationship between seeking future urgent healthcare and anxiety in patients diagnosed either with CHD, asthma, diabetes or COPD, found no relationship (Blakely et al., 2014). Blakely suggests that many previously reported associations were limited by being cross-sectional concurrent associations only.

One further response to health threats is that of denial. It has been shown that people who engage in denial generally show reduced symptom perception and report, and greater delay in seeking help (Jones, 1990; Zervas et al., 1993). Unrealistically optimistic beliefs about health status or illness outcomes were thought to reduce symptom report and preventive health behaviour by means of increasing the presence of denial. However, neither of these relationships was upheld in a study of symptom report among those with either multiple sclerosis or insulin-dependent diabetes (de Ridder et al., 2004). Aspinwall and Brunhart (1996) have pointed out that optimism is not necessarily unrealistic and maladaptive, but that optimistic beliefs may actually benefit symptom report by enabling people to attend to symptoms without perceiving them as a threat. Tromp et al. (2004) offer support for this from a study of predictors of delay among patients with head and neck cancer, where delay was found to be greater (> three months) in those scoring low on optimism, as well as low on active coping, the use of social support and low **health hardiness**.

Emotion itself may be insufficient to determine health-care-seeking behaviour, given the previously described importance of illness prototypes, symptom perception and interpretations, treatment beliefs, and lay referral behaviours and responses, all of which act together to shape a person's response to a health threat. A person who is highly anxious about a symptom and believes it signifies a terminal illness for which there is no treatment is less likely to seek medical attention quickly than someone who is equally anxious but believes that the symptom may be an early warning sign of a condition for which preventive or curative treatment is available.

Finally, following diagnosis, Kasl and Cobb describe how people engage in sick role behaviour, as the symptoms have been validated (and may increase once a label has been attached to them; Kasl and Cobb 1966b). People are then working towards getting better, adjusting to changed circumstances, or preserving health such as avoiding activity or further injury. Seeking health care does not inevitably lead a person into the sick role, as this will depend on whether speedy and effective treatment is available that enables them to carry on as usual. For those, however, who face ongoing illness, there is a further set of challenges to be met, in terms of impact and outcomes for the patient (Chapter 14 ☛), and secondly in terms of the illness impact upon family and friends (Chapter 15 ☛).

**health hardiness**
the extent to which a person is committed to and involved in health-relevant activities, perceives control over their health and responds to health stressors as challenges or opportunities for growth

## SUMMARY

This chapter has described the various processes that people go through before deciding that they might be getting ill. We have described how people may or may not become aware of certain bodily signs, depending upon the context or upon individual characteristics. Both internal and external factors influence the extent to which a person attends to their own bodily states, and how they subsequently interpret bodily signs as symptoms. We have used as examples throughout a range of common and less common health conditions, including the recent and possibly ongoing COVID-19 pandemic. We have described how, upon interpreting bodily signs as symptoms of some underlying illness, a person compares them with pre-existing illness prototypes derived from their personal experience or from external sources of information. People's beliefs about illness have commonly been found to cluster around key domains: perceived identity (label), timeline, consequences, cure–control, cause and coherence and research has shown that ways of thinking about illness are relatively stable across various patient groups, but may differ from that of a healthy person. Finally, we have described health-care-seeking behaviour as a pathway that can often be a long one with many factors influencing it, and with delay in seeking health care often risking one's health.

At each stage a range of relevant individual, cultural, social and emotional influences have been summarised. Health psychology has an important role to play in identifying the factors that contribute to this journey from symptom perception to healthcare in order to maximise the likelihood of positive health outcomes for patients. How people communicate with health professionals and engage in their treatment is discussed in the following chapter.

## Further reading

Kirsch, I. (2018). Placebo and nocebo. In: C.D. Llewellyn et al (eds.), *The Cambridge Handbook of Psychology, Health and Medicine*, 3rd edition Cambridge: Cambridge University Press, pp. 93–96.

An up-to-date review of findings around the complex phenomenon of placebo and nocebo effects with a discussion of the different explanations offered i.e. classical conditioning theories, modelling, and response expectancy theory.

Rosendal, M., Jarbøl, D.E., Pedersen, A.F. et al. (2013). Multiple perspectives on symptom interpretation in primary care research, *BMC Family Practice*, 14: 167

A well written summary of the factors influencing symptom perception, interpretation and response, highlighting the relevance of these to healthcare practice.

Ziebland, S. and Wyke, S. (2021). Health and illness in a connected world: how might sharing experiences on the internet affect people's health. Milbank Quarterly, 90: 219–249.

A fascinating realist review of studies of the various means by which individuals share their symptom illness and treatment experiences online and the impact of this on health and behavior – interestingly and importantly the authors check and discuss their interpretation of the review findings with a service user panel before confirming their conclusions.

Visit www.healthtalkonline.org for video and interview material derived from a wide range of rigorous research interviews with people who have direct experience with a wide range of health conditions. Qualitative material such as provided here from study can be both insightful and helpful when developing your own research ideas.

# Chapter 10

# The consultation and beyond

## Learning outcomes

By the end of the chapter, you should have an understanding of:

- the process of the medical consultation
- the movement towards 'shared decision making' and the issues it creates
- factors that contribute to effective and ineffective consultations with health professionals
- issues related to 'breaking bad news' and medical decision making
- factors that influence adherence to medical treatments and behavioural change programmes
- interventions to improve adherence to medication and behavioural regimens

## Doctor error causes heart attack death

This is a headline that could probably be written in the newspapers every day. But this error was not the fault of long waiting lists, giving the wrong drugs, or poor surgery. Rather, it was the result of the doctor's communication with the patient – or rather their lack of it. Mr Jones who had a history of anxiety went to his General Practitioner about a mild pain in his chest that had been going on for some hours. Unfortunately, for him, Mr Jones was what doctors sometimes call a 'heart sink' patient – the doctor's heart sinks when they see them come in the door, because they know the patient will make several complaints of a very general nature that they will not be able to treat, and the patient will return in the next few weeks with new complaints – which will again be untreatable. Even more unfortunately, the doctor then acted on her assumption that this was the case rather than trying to get a full picture of Mr Jones's symptoms and without conducting relevant tests. The doctor took charge of the consultation, asking closed questions about the symptoms, and confirmed to her satisfaction that the symptoms were psychosomatic in nature. She gave some reassuring words to Mr Jones, who left feeling somewhat disappointed by the relatively brief consultation and still doubtful that his symptoms were not more serious. However, he followed the doctor's advice and did not seek further medical help. Later that day, he died of a heart attack at home. In this chapter we cover the two key issues that may have contributed to this outcome: the doctor adopting a medically led interview style that did not allow the patient to volunteer information they considered relevant to the case, and their use of faulty diagnostic heuristics. Together, they proved fatal.

## Chapter outline

**Conversations between healthcare providers and patients are one of the most important means through which both groups give and receive information relevant to medical decisions, treatment and self-care. As such, the consultation remains one of the most important aspects of medical care. Good communication enhances the effectiveness of care; poor communication can lead doctors to make poor diagnoses and treatment decisions and leave patients feeling dissatisfied and unwilling or unable to engage appropriately in their own treatment. This chapter considers a number of factors that contribute to the quality of the consultation, and how doctors, other healthcare workers, and patients act on information gained from it. It starts by examining the process of the consultation – what makes a 'good' or a 'bad' consultation. It then considers how doctors use the information given in the consultation to inform their diagnostic decisions. Finally, the chapter considers how factors in the consultation and beyond influence whether and how much patients follow medical treatments or behavioural programmes recommended in it.**

# The medical consultation

## The nature of the encounter

Consultations are a time in which doctors and other health professionals can obtain information to inform their diagnostic and treatment decisions, and patients can gain information about their condition, its treatment, and discuss issues relevant to them. They typically include five phases:

1. establishing rapport;
2. identifying the reason for the patient's attendance;
3. a verbal or physical examination, discussion of relevant issues, or both;
4. evaluation of the implications of stage 3;
5. decisions about future treatment and care.

These phases appear to hold for most consultations, although, as we consider later, what happens within each 'stage' can vary significantly. Another way of exploring the consultation is to consider the key elements that make for a successful interview. Ford et al. (2003) identified six factors considered to be important to a 'good' medical consultation by a variety of informants including general practitioners, hospital doctors, nurses and lay people. They involve the health professional:

1. having a good knowledge of research or medical information and being able to communicate this to the patient;
2. achieving a good relationship with the patient;
3. establishing the nature of the patient's medical problem;
4. gaining an understanding of the patient's understanding of their problem and its ramifications;
5. engaging the patient in any decision-making process – treatment choices, for example, are discussed with the patient;
6. managing time so that the consultation does not appear rushed.

## Who has the power?

The consultation involves both patient and health professional: and both can contribute to its outcome. The nature of the meeting, however, means that the health professional usually has more power over the consultation than the patient. This power differential can be exacerbated by the patient's behaviour and expectations within the consultation. They may often defer to the professional and be reluctant to ask questions or challenge any conclusions they may make. Such behaviour is more likely to occur in consultations with doctors than with other health professionals, such as nurses. Nevertheless, all health professionals have significant responsibility for determining the style and outcome of the consultation. This can result in approaches differing from 'doctor knows best', a professional-centred approach identified by Byrne and Long (1976), to a more patient-centred approach (e.g. Kurtz et al., 2003). Characteristics of the former are:

- The health professional keeps control over the interview.
- They ask questions in order to gain information. These are direct, closed (allow yes/no answers), and refer to medical or other relevant facts.
- The health professional makes the decision.
- The patient passively accepts this decision.

Characteristics of the patient-centred approach include:

- The professional identifies and works with the patient's agenda as well as their own.
- The health professional actively listens to the patient and responds appropriately.
- Communication is characterised by the professional encouraging engagement and seeking the patient's ideas about what is wrong with them and how their condition may be treated.
- The patient is an active participant in the process.

Over the past decade, there has been a gradual shift from the professional-centred model to the patient-centred approach. Increasingly, both health professionals and patients are seen as collaborators in decisions concerning patient healthcare. This is perhaps most strongly expressed in a movement among health professionals towards a process of 'shared decision making' (Elwyn et al., 2017) in which the patient and health professional have an equal share (and responsibility) in many treatment decisions. The process of shared decision making is illustrated by Elwyn et al.'s (2017) consultation approach which involves the following steps:

- *Team talk*: health professional and patient work together as a team to describe the various treatment choices goals and determine the patient's goals in relation to them.
- *Option talk*: health professional and patient discuss the various treatment options in more detail using risk communication principles. These 'risk communication principles' involve provision of information in ways consistent with the informational style of the patient. Decisions may be facilitated by developing a list of appropriate information in relation to the treatment provision. This may involve a range of factors including likely treatment options, risk for future disease, implications for lifestyle and so on, in relation to each treatment option. Care needs to be taken to provide information in accessible ways. Some patients, for example, may be comfortable with discussion of percentage outcomes. Others may prefer visual presentation of information including 'thermometer scales', crowd figures (for example, showing how many of 100 people are affected), survival curves, or pie charts (Edwards, Elwyn and Mulley, 2002). The key is to identify the best way to present information to the patient and to use this as the basis for discussion.
- *Decision talk*: based on the information and patient preferences identified in the first two stages, the patient is encouraged to come to a final treatment decision.

Advocates of this approach note that it is not relevant to all medical encounters and may only truly occur where there is no dominant choice of treatment – a situation referred to as equipoise. This may occur in the context of very important health issues, such as a woman with breast cancer deciding whether or not to conserve a breast with a **lumpectomy** or to have more radical surgery and remove the whole affected breast. Here, there is no differential medical benefit from either approach (i.e. equipoise), and the choice may be more determined by factors such as the patient's concerns over their appearance or their desire to feel confident they will not experience a

lumpectomy

a surgical procedure in which only the tumour and a small area of surrounding tissue are removed. Contrasts with mastectomy in which the whole breast is removed recurrence. Where equipoise does not exist, for example, in the case of a request for antibiotics for the treatment of a viral condition (where they will be of no benefit), the health professional may educate the patient to help them understand or accept the health professional's choice of treatment, and so arrive at a 'joint decision', but not a truly shared decision.

Both shared and joint decision-making approaches are now advocated by, among others, the key British health-care policy body (NICE), which has called for 'active partnerships' between health professionals and patients (NICE, 2021). As a consequence, this type of consultation style is increasingly used by a range of health professionals, including doctors, nurses, and by professionals where information provision has historically been a one-way process, such as chiropodists and pharmacists (e.g. Barnett et al., 2019).

Despite this enthusiasm, there are often power differentials between high-status health professionals (particularly doctors) and patients within the consultation. The health professional, for example, typically has more relevant knowledge than the patient. The appearance of equality can therefore be an illusion rather than reality, and both health professionals and patients may find it difficult to move away from this implicit power structure. Indeed, many patients *prefer* this asymmetry and resist moves to 'empower' them into a decision-making role. Some patients may be distressed and worried if a health-care professional admits there is no clear evidence about the best choice of intervention, or that the evidence is mixed or premised on poor methodology. By contrast, being prescribed a particular treatment by an expert health professional may confer certainty and reassurance in the treatment of disease that cannot be found when the patient is asked to make choices about a number of uncertain treatment options.

Empirical research confirms some of these cautions. Marahrens et al. (2017), for example, identified the treatment-decision making preferences of a sample of over 800 patients in the treatment of diabetic retinopathy. Three quarters of them preferred full shared-decision making between doctor and patient, 17 per cent wanted doctor led decisions, while a smaller number wanted to be the primary decision maker. Patients wanting doctor led decisions were older, less educated, and had a higher frequency of consultations over the year. Unsurprisingly, perhaps, patients with better basic knowledge of their condition and who regularly monitored it were less likely to prefer doctor-led decision making. Interestingly, the majority (52 per cent) of patients in a Malaysian sample of primary care patients – in a culture usually considered to prefer a more passive role in decision making – also favoured joint decision making (Ambigapathy, Chia and Ng, 2016). Individuals with an active coping style, who have more education, and a severe health problem are most likely to want to be engaged in the decision-making process (Arora and McHorney, 2000). However, Arora and McHorney also found that people who placed the highest value on their health were least likely to want to be engaged in the decision-making process – perhaps because they considered this to be such an important issue that they did not want to question the expert opinion of the doctor.

Whatever the preferences of patients, the stated preferences of doctors are shifting from doctor-led to patient-based communication styles. In a survey of over 1,000 US physicians, for example, Murray et al. (2007) found that 75 per cent preferred to share decision making with their patients, 14 per cent preferred paternalism, and 11 per cent preferred consumerism (patient knows best). Nearly 90 per cent considered themselves to be practising their preferred style.

Despite these stated preferences for shared or joint-decision making, many patients do not experience this approach. Amundsen et al.'s (2018) observational study of cancer specialists, for example, found levels of shared decision making to be 'low'. This may reflect a natural style of the clinicians, although technology may also be contributing to this behaviour. Bensing et al.'s (2006) analysis of Dutch family doctors' consulting styles, for example, revealed that over the 15 years before their report, consultations had become increasingly medically led and interrupted by frequent recording of information on computer. In addition, Robertson et al.'s (2011) discourse analysis of treatment decisions made in general practice found that so-called 'partnership talk' which was designed to engage patients in decision making was actually used to minimise resistance to medically suggested treatment approaches, and doctors worked to achieve (medically led) consensus rather than involvement. Patient-centred communication may also be affected by the nature of the problem being resolved. Family doctors, for example, appear more likely to engage in joint decision making when patients present with physical rather than psychological or other problems (Bodegård et al., 2019).

Finally, there are data suggesting that patients are demanding increasingly complex communication with their doctor, and some are finding this difficult to provide. In 2017, a commentary in the *British Medical Journal* (Abdelrahman and Abdelmageed, 2017) noted that most complaints against doctors are a result of poor communication. The three most common complaints to the General Medical Council (British doctors' regulatory body) were related to concerns with investigations and treatment, problems with communication, and a perceived lack of respect for the patient. They also noted increasing evidence that poor communication and lack of empathy are major causes of adverse events, patient dissatisfaction, and, therefore, complaints (e.g. Woodward-Kron et al., 2014).

Overall, consultations that involve patients in decision making result in high levels of patient satisfaction, confidence in healthcare recommendations, improvements in self-care and wellbeing, and, on occasion, fewer drug prescriptions and less demand for inappropriate surgical treatments. They also appear to have similar, but no better, medical outcomes to more traditional consultation approaches (e.g. Krones et al., 2008). Indeed, medical outcomes may not always be optimal. Kinmonth et al. (1998), for example, found that patients who were given a patient-centred approach to the treatment of their type 2 diabetes expressed higher levels of satisfaction with their communication with health professionals, greater treatment satisfaction, and greater wellbeing than patients who received a standard health-professional-led consultation. However, they were less careful in sticking to the calorie-controlled diet necessary to maximise control over their condition. This may not be a bad outcome, of course. Rather, it is possible that patients may have knowingly opted to have a higher day-to-day quality of life rather than one constrained by medical 'necessities'.

# Factors influencing the consultation

## Working together

A variety of factors may influence the behaviour of health professionals, some of which may be of no immediate medical relevance, but certainly impact on the communication process. Unsurprisingly, perhaps, health professionals give more information to patients they like than those they dislike. Encounters may also be influenced by the time available, the type of problem being dealt with, and so on. Patients and health professionals may also hold different agendas and expectations of the consultation. Patients are frequently concerned about issues such as pain and how an illness may interfere with their everyday lives. Health professionals are often more concerned with understanding the severity of the patient's condition and developing their treatment plan. These differing agendas mean that health professionals and patient can fail to appreciate important aspects of any information given and received. They may also impact on the outcome of the consultation.

In one study of this phenomenon, Langewitz et al. (2009) found some elements of doctor behaviour that actively benefited the consultation. The use of **reflection** and **mirroring** patient communications, for example, resulted in higher levels of patient disclosure of information related both to their medical condition and its psychosocial consequences. However, this increase in information led to a recording of medical information only in the doctors' notes: personal, non-medical, information was disregarded. Patients tell physicians about things they deem important for the physician to know; physicians filter this out, and essentially record medical information they deem appropriate. Whether this affects subsequent care is as yet unknown.

The findings of Zachariae et al. (2003) are also relevant here. They found that patients' ratings of how well they considered physicians understood their feelings during the consultation, whether they attempted to gain an understanding of their viewpoint, and the quality of their contact with the doctor were as important as their confidence in their doctor's ability to handle the medical

**reflection**

involves listening to and feeding back understandings of the feelings of an individual, rather than simply the content of their statements

**mirroring**

a therapeutic technique in which the therapist repeats back to a client, usually as a paraphrase but sometimes word for word, the idea that has just been expressed aspects of their care in predicting satisfaction with the interview, their confidence in their ability to cope with their illness, and levels of emotional distress. Of note also was that doctors who evidenced poor communication skills were least aware of the patients' responses and level of dissatisfaction with the interview. The importance of empathy, as described by Zachariae, has been consistently shown to improve patient satisfaction, facilitate information transmission and lower patients' anxiety. In addition, it can increase the perceived expertise of the health professional and the inter-personal trust afforded them by their patients. Together, these factors lead to stronger patient-clinician partnerships and higher levels of adherence to treatment regimens (e.g. Flickinger et al., 2016).

## The type of health professional

As well as these subtle differences in skills and personal characteristics, more obvious factors may also influence the style of the encounter. The style of interaction appears to differ across professions. Nurses, for example, are generally seen as more nurturing, easier to talk to and better listeners than doctors. These different roles were highlighted by Nichols (2003) who suggested that doctors may find it difficult to become emotionally involved or to know their patients as people when they are involved in life and death decisions or actions such as surgery. With this in mind, he suggested that nurses should provide the main 'caring' role and be more involved in holistic care of the individual. Perhaps for this reason, nurses typically address more psychosocial concerns than doctors, and have different styles of talking to patients. Vinall-Collier et al. (2016), for example, found that nurses' communication frequently involved responding to patients' contributions, took more care to build relationships, provided emotional support, and allowed patients to tell their story more than physicians. In addition, Barratt and Thomas (2018) found that nurses tended to speak in language more familiar to many patients and to communicate a sense of having more time for patients and carers. To assume doctors are always more condition-led and nurses are more caring, however, may be a gross simplification. The nature of any encounter is likely to be a function of both the necessary outcomes of the encounter and the time pressures in which most consultations occur (Vinall-Collier et al., 2016).

**Photo 10.1** Being a friendly face and expressing empathy can help patients cope with bad news. Here an occupational therapist discusses therapy options with someone with a progressive muscular disorder in a completely informal and 'non-medical' manner

*Source*: Rob Lewine/Tetra Images/Getty Images.

### The gender of the health professional

The gender of the health professional may have a significant influence the nature of the consultation. Jefferson, Bloor and Hewitt's (2015) meta-analysis showed that medical visits with female physicians were, on average, two minutes (10 per cent) longer than those of male physicians. During this time, female physicians typically engage in significantly more patient-centred communication: active partnership behaviours, positive talk, psychosocial counselling, psychosocial question asking, and emotionally focused talk, particularly when working with female patients (Sandhu et al., 2009). In addition, the patients of female physicians spoke more overall, disclosed more biomedical and psychosocial information, and made more positive statements to their physicians than did the patients of male physicians. Of course, this may reflect not only the nature of female doctors' consultation style; it may also reflect patient expectations and responses to stereotypes of female doctors. Reflecting this possibility, satisfaction with female doctors is likely to be high only when they adopt what are perceived to be gender-role congruent communication styles (Schmid Mast et al., 2007). Indeed, stereotypes of doctor competence may actively impair communication and likely outcomes of consultations. Himmelstein and Sanchez (2016), for example, found that men high on a measure of masculinity typically believed that male physicians were more competent than female clinicians and, if given a choice, would choose them as their clinician. However, when interacting with them, they were less likely to disclose symptoms than if they were consulting with a female doctor; presumably as a consequence of the need to maintain their 'masculinity' and not appear weak in front of a fellow male (see further discussion of this phenomenon in Chapter 2 ☛).

## Culture and language

Culture and language are inextricably linked in the context of the consultation, and there is clear evidence that people from differing cultures and languages will experience differing styles of consultation (see also Chapter 2 ☛). The optimal consultation appears to occur when patients consider themselves to be similar to the health professional on a range of characteristics, including life values and spiritual beliefs. These assumptions may be inferred, at least in part, from the ethnicity (and gender) of the healthcare professional. Accordingly, the most highly rated consultations tend to occur when patient and healthcare professional are ethnically similar (Street et al., 2008). This may be facilitated by the potential for mutual understandings of culture, language and health priorities.

Where patient and healthcare provider are discordant, difficulties may arise. One UK research group (Neal et al. 2006), for example, found that South Asians fluent in English had the shortest consultations with their family doctors; South Asians not fluent in English had the longest. White patients discussed more emotional problems than the South Asian patients and were more active during the consultations than either of the Asian groups. In the Netherlands, consultations with immigrant patients (especially those from Turkey and Morocco) are likely to be significantly briefer, and the power distance between patient and doctor greater than those with Dutch patients. Doctors have also been shown to invest more effort in trying to understand immigrant patients, while they showed more involvement and empathy with those that were Dutch (Meeuwesen et al., 2006). Problems in communication may result in doctors experiencing difficulties in reaching appropriate diagnoses (e.g. Okelo et al., 2007) and patients misunderstanding information given in the consultation (e.g. Jones et al. 2007). The likelihood of these communication errors may be increased as a consequence of many health professionals' overestimation of the level of language understanding these patients have (Kelly and Haidet, 2007). Translation by others when the patient does not speak the same language as the clinician may not always help, and can be actively problematic, particularly when 'helpful' friends are translating and embellishing and changing what is being said (Turner and Madi, 2019). Culture-related difficulties may even be exacerbated by health professionals' inaccurate expectations of how patients expect to be treated. Fagerli et al. (2007), for example, found that their sample of Norwegian health professionals thought that Pakistani-born patients preferred an authoritarian health-worker style. In fact, they preferred empathy and care. This disparity resulted in a lack of trust between patients and professionals.

## Using the right language

One obvious factor that will influence the degree to which patients understand what is said in a consultation is the language used within it. Technical or medical language can be confusing unless appropriately explained. Even relatively simple technical language can be confusing. Dua, Vassiliou and Fan (2013), for example, found that 60 per cent of their patients thought a bone fracture was a crack in the bone, and less severe than a broken bone (it isn't). In a study of patients' understandings of words used to describe 'lumps', Chadha and Repanos (2006) found that a majority were unaware of the meaning of words such as 'sarcoma' and 'lipoma'. While this confusion may be expected, 19 per cent of patients thought that a 'benign' lump was a malignant cancer; a serious misunderstanding. Not surprisingly, the use of jargon may result in significant anxiety. Finally, Abramsky and Fletcher (2002) found that the words rare, abnormal, syndrome, disorder, anomaly and high risk in the context of genetic screening were particularly worrying to patients. They also found that risk for developing a disorder expressed as '1 in X' evoked more worry than when the same information was expressed as a percentage. These subtle uses of language show how careful health-care professionals need to be when talking to patients.

### Patient factors

The characteristics of patients may also influence the consultation. High levels of anxiety or distress during the interview, a lack of familiarity with the information discussed, a failure to actively engage with the interview, and not having considered issues to be discussed within the consultation may minimise patients' level of engagement. Patients may not think through what information they want or realise only after the interview what they could have asked. Perhaps for these reasons, people who are well educated, and in particular those with high 'health literacy' (Heuser et al., 2019) tend to gain more information and to have longer consultations than people with low levels of education and health literacy. Unsurprisingly, perhaps, other factors that can increase patient-instigated communication include experiencing high levels of symptom concern and familiarity with the clinician being consulted (Fenton et al., 2019). Broader factors such as high levels of quality of life satisfaction, and personality characteristics including extraversion have also been found to predict levels of patient engagement (e.g. Geesink et al., 2018).

## Improving communication

There are two broad ways in which communication between patients and health professionals can be facilitated: (i) training professionals in the required skills, and (ii) supporting patients in the process of negotiating the consultation and decision-making. One simple approach to this second goal is through a process known as 'patient coaching'.

### Patient 'coaching'

Coaching involves preparing patients for encounters with health professionals. This can involve prompting or even training them to prepare questions, using 'prompt sheets', to which they want answers. One example of this approach can be found in the UK NHS website (www.nhs.uk/using-the-nhs/nhs-services/gps/what-to-ask-your-doctor) which provides a detailed question checklist of potential questions to ask and issues to consider at differing stages of diagnosis and treatment. These include:

- Tests, such as blood tests or scans
  - What are the tests for?
  - How and when will I get the results?
  - Who do I contact if I don't get the results?
- Treatment
  - Are there other ways to treat my condition?
  - What do you recommend?
  - Are there any side effects or risks? If so, what are they?
  - How long will I need treatment for?
  - How will I know if the treatment is working?
  - How effective is this treatment?
  - What will happen if I don't have any treatment?
  - Is there anything I can do to help myself?
- What next
  - What happens next?
  - Do I need to come back and see you? If so, when?
  - Who do I contact if things get worse?
  - Do you have any written information?
  - Where can I go for more information?

### Top tips

- Before your appointment
    - Write down your two or three most important questions.
    - List or bring all your medicines and pills – including vitamins and supplements
    - Write down details of your symptoms, including when they started and what makes them better or worse.
    - Ask a friend or family member to come with you, if you like.
- During your appointment
    - Don’t be afraid to ask if you don’t understand. For example, ‘Can you say that again? I still don’t understand.’?
    - If you don’t understand any words, ask for them to be written down and explained.
    - Write things down or ask a family member or friend to take notes.
- Before you leave your appointment

  Check:
    - You’ve covered everything on your list
    - You understand, for example ‘Can I just check I understood what you said?’
    - You know what should happen next – and when. Write it down.

  Ask:
    - Who to contact if you have any more problems or questions
    - About support groups and where to go for reliable information
    - For copies of letters written about you – you are entitled to see these.
- After your appointment, don’t forget the following
    - Write down what you discussed and what happens next. Keep your notes.
    - Book any tests that you can and put the dates in your diary.

  Ask:
    - What happens if I’m not sent my appointment details?
    - Can I have the results of any tests? If you don’t get the results when you expect – ask for them. Ask what the results mean.

Overall, the evidence suggests that this approach can facilitate appropriate information provision and increase patient satisfaction (see Liqurish et al., 2019). Amundsen et al. (2018), for example, found that provision of a prompt list increased the number of questions concerning prognosis, the disease, and quality of treatment in an outpatient cancer clinic. In a similar study population of patients with oesophageal cancer, Smets et al. (2012) also found patients asked significantly more questions following the use of prompts (an average of 12 versus 8 in a non-prompt condition), although their interviews did not differ in length and patients in both conditions reported equal satisfaction with the consultation. Improved information provision may also help to allay patients’ anxiety in the longer term (Brandes et al., 2015); presumably because concerns have been addressed that otherwise would not have been.

Despite this positive evidence, the approach does not provide an infallible means of enhancing communication, which may still be powerfully influenced by other factors. Frost et al. (2019), for example, found that even simple attempts to improve communication can be heavily influenced by the communication preferences of both patients and clinicians. In a sample of patients attending an outpatient appointment with a consultant concerning their diabetes, for example, they found that where both patients and consultants preferred a consultant-led or patient-led consultation, an intervention designed to increase use of a checklist facilitated both communication and decision making. However, where there was no consensus, there was no benefit.

## ‘Skilling up’ healthcare practitioners

The antithesis of helping patients to be more active in consultations involves training healthcare practitioners to be supportive of enhanced communication and interaction within the consultation. This may not be easy.

On a positive note, Noordman et al. (2019) found significant reductions in the use of computers during consultations and increases in empathy following a three-day training programme involving education on the basics of patient-centred communication and empathy, practicing with actors, followed by review and reflection on these videos. More cautiously, a Cochrane review of the 17 trials evaluating the outcomes of training programmes in healthcare professionals working with patients with cancer (Moore et al., 2018) found evidence of gains on measures of the frequency of open questions and shows of empathy, and fewer clinicians only providing ‘facts’. However, there were no gains on measures of eliciting patient concerns and providing appropriate information, clarifying and/or summarising information, and negotiation. In addition, despite some of the stereotypes of differing communication styles, no differences were found between nurses and doctors taking the course; nor, sadly, neither did patients' satisfaction or views on participants' communication skills improve.

## The bad news consultation

One particular type of consultation for which the necessary skills have received particular attention is called the 'bad news' interview. As its name implies, these interactions are typically those in which patients and/or their partners are told that they have a serious illness or that they may die of their illness. Clearly, such interviews are stressful for both patients and health-care professionals. Historically, information about the likelihood of dying has frequently been withheld from patients – although their relatives were frequently told, placing a significant burden of knowledge on these people. However, this is no longer considered ethical – patients are now considered to have the right to be told their prognosis.

There is consistent evidence that the way in which bad news is given will impact on patient wellbeing (P. Schofield et al., 2003). Unfortunately, there is little evidence about the best methods of doing so, and most guidelines are based on opinion and basic principles of good communication rather than empirical data. One of the best-known process models of this approach is the six stage SPIKES model of Baile et al. (2000):

### Step 1: S – Setting up the interview

This involves mentally rehearsing the likely plan of how the interview will proceed and setting up the physical setting in an appropriate way.

- *Arrange for privacy*. Ideally, a private room; certainly, a place where no one can overhear the meeting or intrude on it.
- *Involve significant others*. Most patients want to have someone with them at this time, whether it be friend of family member. However, this should be their choice.
- *Sit down*. Sitting down relaxes the patient and is a sign you will not rush. Avoid barriers between you and the patient.
- *Make connection with the patient*. This may be enhanced by appropriate eye contact and touching or holding an arm or hand.
- *Manage time constraints and interruptions*. Inform the patient of any time constraints you may have.

### Step 2: P – Assessing the patient's Perceptions

- Use open-ended questions, such as 'What have you been told about your medical situation so far?' to gain an understanding of how the patient perceives their medical situation: what it is and whether it is serious. It can also allow the clinician to determine if the patient is engaging in any denial of their situation or has unrealistic expectations of treatment.

### Step 3: I – Obtaining the patient's Invitation

- The goal of this stage is to determine how much the patient wants to know about their diagnosis. They may be asked questions such as 'How much information would you like to know about your test results? Would you like to give all the information, or just look at the treatment plan?' If patients do not want to know the details of their condition or prognosis, the clinician may offer to answer any questions they have in the future or to talk to a relative or friend.

### Step 4: K – Giving Knowledge and information to the patient

- This is the stage in which the 'bad news' is given. Some verbal warning of the message may lessen any shock the patient may experience: 'I'm sorry to say, but I have some bad news to tell you ... '. Information should then be given in non-technical language ('your cancer has spread' rather than 'your cancer has metastasized') avoiding phrases such as 'You have very bad cancer and unless you get treatment immediately you are going to die.' Information should be given in small 'chunks' with checks that the patient has understood the information given at regular intervals. Finally, phrases such as 'There is nothing more we can do for you,' should be avoided. Such phrases are inconsistent with possible patient therapeutic goals such as good pain control and symptom relief.

### Step 5: E – Addressing the patient's Emotions with empathic responses

- Responding to the patient's emotions is perhaps the most difficult challenges of breaking bad news.

Patients' emotional reactions may vary from silence to disbelief, crying, denial, or anger. The clinician can be supportive through the use of empathic responses, which themselves involve a series of processes:

- Observe for any emotion on the part of the patient.
- Follow and identify the emotions experienced by the patient. If they appear sad but silent, the clinician should use open questions to find what they are thinking or feeling.
- The reason for the emotion should be identified. It is easy to assume this is due to the bad news, but it may not be clear which issue is of concern.
- After the patient has been given a brief period of time to express his or her feelings, the clinician should respond to their distress through empathic feedback: 'I can understand that the test result was not what you were hoping for.' The clinician may also move closer to the patient and provide some physical comfort by, for example, touching their arm or hand.
- Any further medical dialogue needs to be suspended until the patient is able to re-engage with it. This may take some time, during which the clinician may provide more empathic responses ('I too wish the news had been better') and respond to issues raised by the patient in an empathic and non-technical manner.

### Step 6: S –Strategy and Summary

- Having a clear treatment plan will reduce anxiety and uncertainty but should be discussed only after patients are ready to address these issues. Where possible a shared decision approach should be taken so that patients feel involved in their care, and understand their clinician considers their wishes to be important. As before, it is important to check the patients' understanding of the issues as the discussion continues to ensure they do not become inappropriately optimistic (or pessimistic) about the likely outcome of any treatment plan.

When these, or similar, guidelines are followed, patients appear to benefit. M. Schofield et al. (2003), for example, asked patients to recall a **bad news interview** in which they received information about a 'life threatening' **melanoma**. They were asked questions about how their diagnosis was given, whether they received as much information as they wanted about their diagnosis, its treatment options, and its prognosis, and how the interview was conducted. They examined the relationship between their responses and levels of anxiety and depression at the time of diagnosis, 4 and 13 months later. Factors associated with low levels of anxiety included the health professional preparing the patient for their diagnosis, giving as much information as required, providing written information, talking about the patient's feelings, being reassuring, and the presence of other (supportive) people while being given the diagnosis. Practices associated with low levels of depression included encouraging the patient to be involved in treatment-related decisions and discussing the severity of the diagnosis and how it may affect other aspects of their life.

## WHAT DO YOU THINK?

Many doctors considered it a kindness not to tell patients when they were dying: a belief that also obviated *their* need to go through this painful process. Indeed, so common was this practice that a rule of thirds was often cited as relevant to this situation. That is, two-thirds of patients were assumed to wish to know their prognosis, and two-thirds of doctors did not want to tell them. It is now considered a patient's right to know they are dying, and the practice of telling the relatives and not the patient is no longer acceptable (although the SPIKES protocol outlined above does allow for this).

Patients may be upset, or even distraught, when given such information. However, knowledge of a poor prognosis can allow them to prepare for death: from the most prosaic preparation such as making sure bills are paid to dealing with relationship issues and more existential aspects of their lives. When death is not immediate, patients may prepare life goals that they wish to achieve before they die, and so on. So, there are both positive and negative issues to be considered. Do the benefits outweigh the costs? Perhaps this decision can only be made on an individual basis. But on what grounds? Or perhaps all patients should be told whatever their circumstances?

**bad news interview**
conversation between health professional (usually a doctor) and patient in which they are told 'bad news', usually that their illness has a very poor prognosis, and they may die

**melanoma**
a form of skin cancer. Usually begins in a mole and has a poor prognosis unless treated early.

Having identified 'best practice', a number of studies have examined how well physicians actually give bad news. Farber et al. (2002) found that over half their sample of junior doctors reported always or frequently performing 10 of 11 emotionally supportive strategies (e.g. ask about patients' worries, fears and concerns) and engaging 6 of 9 environmental supports (e.g. ensure that the patient has a support person present). Similarly, Chadha and Repanos (2006) found that 64 per cent of their sample of surgeons felt confident in their ability to break bad news (compared to 91 per cent who felt confident in gaining consent to surgery and 40 per cent who felt confident in discussing 'do not resuscitate' decisions).

These optimistic self-ratings may be contrasted with the findings of Ford et al. (1996), who used audiotapes of consultations to analyse cancer specialists' bad news interviews with their patients and found that the majority of time was spent giving biomedical information with relatively little emphasis on empathic responses or acknowledgment of distress. In addition, the doctors exerted significant levels of control over the interview, moving away from the patient-led interview that the guidelines indicate as being optimal. Another observational study by the same group (Fallowfield et al. 1990) found that surgeons did not detect 70 per cent of instances of emotional distress in women being diagnosed with breast cancer. These figures may not be improving over time. Indeed, as Atienza-Carrasco et al. (2018) noted, 'the human quality of healthcare has deteriorated due to excessive workloads and ... the role of technology'. Their qualitative study of the discourse of physicians, midwives and nurses found significant gaps in fundamentals of communication during the 'bad news interview' including low empathy and non-judgemental listening. Similarly, Seifart et al. (2014) found less than half the patients in their study reported complete satisfaction in the way the bad news was delivered using the SPIKES protocol. Of course, this may in part be attributable to deviations from the protocol (we have seen that many communication approaches are rarely fully adhered to). Nevertheless, patients indicated that the process could have been enhanced by additional checks to ensure their understanding of the issues and by allowing them to ask a question at any time.

Interestingly, there may be also consistent individual differences in how patients respond or even prefer bad news to be given. Fujimori, Akechi and Uchitomi (2017) found younger patients, women, and those who had strong faith in the clinician providing the news were more concerned with how the issue was handled than older, male patients who were less educated and who had less faith in the clinician.

Health professionals clearly have the potential to benefit from training in communication skills specifically related to end-of-life consultations. And they do potentially benefit from them, although translating skills into real life settings has proven problematic. Curtis et al. (2014), for example, explored this issue in a study involving nearly four hundred health professionals (junior doctors and nurse practitioners) involved in care of patients coming to the end of their lives. They were allocated to either a skills-based training programme designed to enhance their engagement with patients or 'usual education'. The former involved eight, four-hour, sessions led by a senior doctor and nurse. Each session included a brief didactic overview, including a demonstration role-play; skills practice using simulation (simulated patients, family, or clinicians); and reflective discussions. Each addressed a specific topic, including building rapport; giving bad news; nurse-physician conflict; conducting a family conference; and talking about dying. The programme was clearly thorough and focused. Unfortunately, on a measure of 'quality of communication' completed by nearly two thousand patients and family members, no differences were found between control and skills-based groups. While there were clear improvements in skills during the simulated interactions on the course, real world obstacles such as time demands, conflicting interests and so on, compromised the transmission of skills to the real world of patient consultations.

Before ending this section, it should be acknowledged that the bad news interview is stressful for health professionals as well as patients (see Figure 10.1). According to Messerotti (2020), 56 per cent of physicians considered breaking the news of a poor prognosis to be the most difficult task they undertook, and 37 per cent found them significantly stressful. Over time, the repeated necessity to be involved in bad news interviews can take a severe toll on those involved and can result in a condition known as burnout; a state of emotional, mental, and often physical exhaustion brought on by prolonged or repeated stress.

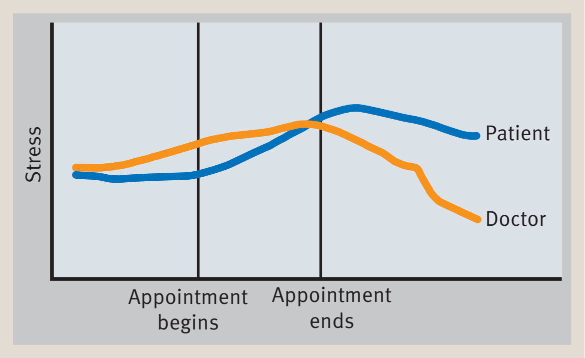


**Figure 10.1** The timescale of stress experienced by health-care professionals and patients in relation to the bad news interview

*Source*: Adapted from Ptacek and Eberhardt (1996).

# Moving beyond the consultation

A key goal of the consultation is to allow healthcare professionals and patients to receive and provide information relevant to medical decision making and treatment. The next part of the chapter considers two outcomes of this process: one involving the healthcare professional, and one involving the patient.

## Medical decision making

Healthcare decisions do not happen in a neutral context; and may be influenced by a wide variety of factors. They may be biased by health-care professionals' expectations of their patients, their fellow professionals, and the sheer pressure of making decisions in a short time – often without all the information necessary to make a fully informed decision. Doctors' own views about the nature of healthcare may also influence their decisions. Some doctors, for example, may only be willing to treat patients who are actively involved in maintaining their own health. Such doctors may refuse to provide expensive curative treatment for smoking-related diseases in patients who are unwilling to give up smoking. Other biases may be less conscious or may be motivated by non-health related issues. Mitchell et al. (2000), for example, found that, even after adjusting for demographic factors, the presence of other serious diseases and ability to pay, African American patients with **transient ischaemic attacks** were significantly less likely to receive specialist diagnostic tests or to see a specialist doctor than white patients (see Chapter 2 ☛ for an extended discussion of this issue). Gender differences may also influence the care people receive in hospital; often favouring males. A higher proportion of men than women, for example, were prescribed opioids for the treatment of acute renal colic pain in an Emergency Department (Naamany et al., 2019), while proportionately more men than women are likely to be offered a place on cardiac rehabilitation programmes (see Chapter 17 ☛) following a myocardial infarction (see Chapter 8 ☛: British Heart Foundation, 2010).

A key area of medical decision making involves diagnosing the illness with which patients present. Elstein and Schwarz (2002) identified a number of ways that doctors achieve this:

- *Hypothesis testing*: the so-called 'gold star' level of decision making. This involves a logical sequencing of establishing and testing hypotheses about the nature of the diagnosis. Hypotheses are established, tested, and when they fail are replaced by further hypotheses until a final 'correct' hypothesis is established.
- *Pattern recognition*: compares patterns of symptoms with disease prototypes. This may be a good way of reaching easy diagnoses, with the hypothesis-testing approach being utilised for more complex decisions.
- *Opinion revision or 'heuristics and biases'*: perhaps the least reliable approach to making diagnoses: involves making decisions based on partial evidence as a result of using rules of thumb or heuristics.

Clearly, most of the diagnoses assigned by doctors are accurate. However, their decision-making may be prone to error, particularly when decisions are made by heuristics. The use of heuristics may be inevitable in the context of medical decisions made at times of crisis or when optimal information may not be available. But the use of these short-cuts can also happen in other, less demanding, situations as well. The most commonly

transient ischaemic attacks

short periods of reduced blood flow to the brain resulting in symptoms including short periods of confusion, weakness and other minor neurological symptoms used heuristics are often those termed ‘fast and frugal’ (Marewski and Gigerenzer, 2012): that is, they aid quick decision making on the basis of minimal information. They allow doctors and other health professionals to make decisions at times of uncertainty but may lead to errors because they are based on assumptions which may or may not be relevant to particular situations, and even more importantly may prevent clinicians from investigating further to obtain information that is. In a qualitative study of this process, André et al. (2002) asked a number of family doctors to describe some of their decision-making processes. One doctor stated that she was so used to 40-year-old men who presented with chest pain being diagnosed with a myocardial infarction (Chapter 8 ☛) she no longer tested for alternative diagnoses (as is recommended practice). Another doctor stated that if he thought a condition was psychosomatic, ‘I begin to try to tie down the idea right away. I won’t start with physical examination before talking about the possibility that it could be something emotional ... ’ – a process that may miss a physical disease process.

A key problem with the use of heuristics is that they limit thinking through the full diagnostic possibilities, and may be biased by a number of factors (O’Sullivan and Schofield, 2018): These include:

- *Availability*: diseases that receive considerable media attention are frequently thought to be more common than they actually are, even by doctors. Similarly, a recent diagnosis by a colleague may increase recall and incorrectly considered likelihood.
- *Confirmation bias*: doctors tend to interpret (and potentially seek) information gained at diagnosis to fit their preconceived diagnosis, rather than the converse.
- *Potential ‘pay off’ of differing diagnoses*: if a diagnosis is unclear, the diagnosis assigned may be the one that carries the least cost and most benefit for the individual. When doctors are presented with a young child complaining of abdominal pain of no obvious origin, for example, a diagnosis of appendicitis and treatment of appendicectomy may be made, as treating the appendicitis successfully may be considered to outweigh the risks associated with an unnecessary operation.
- *Diagnostic momentum/anchoring effect*: continuing a clinical course of action instigated by previous clinicians without considering the available information and changing the plan if required.

One method of improving decision making involves the use of computerised programmes that support doctors in their decision making. One such web-based programme was evaluated by Ramnarayan et al. (2006). This comprised a ‘diagnostic reminder system that provided rapid advice with free text data entry’ that participants could access if they were unsure of a diagnosis. To evaluate its impact, trainee doctors who used the system to diagnose children with acute disorders noted the initial diagnosis they made without the programme and then (when they felt necessary) following its use. These diagnoses were then compared to the diagnosis the child was given prior to discharge from hospital. Before using the programme, 45 per cent of their diagnoses were considered ‘unsafe’; following its use, this figure fell to 33 per cent. To be of use, however, these programmes need to be user friendly. Where they are not, they rapidly fall into misuse and clinicians retreat back to the use of familiar heuristics (Marewski and Gigerenzer, 2012). Overall, similar computerised decision-support programmes do appear to be of benefit; albeit not consistently. In their review of decision-making aids in cancer, for example, Beauchemin et al. (2019) found that of nine studies examining whether treatments improved, five found evidence of significant gains. Of the six measuring patient outcomes, four showed similar levels of improvement. Unsurprisingly, perhaps, computerised support is more likely to be used and of benefit if it is automatically available as a default rather than being accessed ‘on demand’. However, requiring users to respond to the advice given by the system makes little difference to its use (Van der Velde, 2018).

## Compliance, adherence and concordance

A key determinant of the success of any medical intervention is whether patients actually follow the recommended medical regime, whether this involves taking tablets or making more complex behavioural changes. Initially, research into this issue focused on what was termed treatment compliance, which implied a doctor- or health-professional-led process in which the patient was expected to comply with whatever instructions they were given. After several years, the more politically correct term ‘adherence’ was introduced, implying that patients were more involved in the decision-making process; although how this increase in patient independence was achieved was not always clear.

More recently still, the term ‘concordance’ has been introduced reflecting a further development in this process. Here, both health professional and patient reach a jointly determined agreement concerning the treatment regimen. This joint decision requires a patient to be fully informed of the benefits and costs (in terms of side-effects, treatment benefits, etc.) of following a particular treatment regimen. Full concordance between health professional and patient is assumed to increase the likelihood of patients following a treatment plan; although patients may of course change their decision or not follow the agreed treatment for a number of other reasons.

## IN THE SPOTLIGHT

### More heads make worse decisions

Decisions may be affected by a number of factors beyond the consultation. Christensen et al. (2000) examined the effect of group diagnostic decision making involving small teams of junior doctors and medical students. Information given to the groups was manipulated by asking the physicians to individually watch videos of actors acting as patients, offering the same information to all those in the group, and some information unique to each viewer, including one viewer who was given information crucial to making a correct diagnosis.

Their results were interesting in that, once convened, the groups discussed the information common to all those involved more than they discussed the unique information held by each group member. As a result they actually made *more* diagnostic errors than a control group of individual doctors given the same information. These data are particularly pertinent to making difficult diagnoses that may involve discussion by several doctors with information gleaned from a variety of different consultations or to some medical specialties (particularly those involved in mental health) where information from many sources may be used to arrive at a diagnosis.

**Photo 10.2** Some decision-making contexts are more difficult than others. Joint decisions, particularly if led by a powerful consultant, may not always be correct

*Source*: Archives du 7e Art/Photo 12/Alamy Stock Photo.

## Keep taking the tablets

The percentage of people to follow the optimal medical regimen required in many chronic illnesses can be low. It has been estimated that, on average, only half of those prescribed pharmacological therapies take sufficient medication to experience a therapeutic benefit resulting in about 10 per cent of hospital admissions (Schlenk et al., 2004). Looking at more specific disorders, Cramer (2004) reported that between 36 and 93 per cent of patients with type 2 diabetes followed the recommended regimen of **oral hypoglycaemic agents** for between 6 and 24 months. Between 30 - 50 per cent of people are thought to not take all their anti-hypertensive medication), placing them at a nearly six-fold higher risk of dying from a stroke than their more adherent counterparts (Herttua et al., 2013). Krigsman et al. (2007) reported that 42 per cent of their sample were under-using their asthma medication, while 23 per cent were overusing it. Finally, Bernal et al. (2006) reported that 43 per cent of patients with inflammatory bowel disease admitted to missing medication; 20 per cent of patients admitted to self-medicating.

Given the importance of taking these medications, one may wonder why people fail to do so. One simple explanation is that many people forget to take their medication or find their treatment regimen too complicated to cope with effectively. This may be particularly pertinent in the case of complex medical regimes or for people with memory problems, although a range of other factors have also been found to predict sub-optimal use of medication in general (e.g. Kleinsinger, 2018) including:

- *social factors*: including low levels of education, unemployment, concomitant drug use, low levels of social support;
- *psychological factors*: including high levels of anxiety and depression, use of emotion-focused coping strategies such as denial, a belief that continued use of a drug will reduce its effectiveness, taking drug holidays to prevent 'harm' as a consequence of long-term drug use, cognitive impairment;
- *treatment factors*: including misunderstandings regarding treatment, complexity of the treatment regimen, high numbers or fear of side-effects, little obvious benefit from taking medication, poor relationship between patient and health-care provider, poor health professional–patient communication.

**oral hypoglycaemic agents**

various drug types, all of which reduce circulating blood glucose levels

Another contextual factor that may affect adherence with medical regimens, particularly in children, involves the family system. While parental illness beliefs are important determinants of children's adherence to medication (Drotar and Bonner, 2009), less disease-specific family issues have also been determined as important. Dawson (2019), for example, noted adherence to child medication is likely to be low in families characterised as rigid, with low levels of cooperation and communication between family members. From a different perspective, Mellins et al. (2004) found that children's non-adherence with medication was significantly associated with high caregiver stress, poor parent–child communication, caregiver quality of life and caregiver cognitive functioning. Older people also appear less adherent to recommended treatment regimens than younger people. This may not necessarily reflect their attitudes towards medicines, though, as factors such as impaired cognition, depression, and complexity of medication regimens may all impact on adherence (e.g. Smith et al., 2017; Hennein et al., 2018).

A more theoretical perspective on adherence to medication is based on an extension of the illness representations model (Horne and Weinman, 1999) (Chapter 9 ☛). Their model identified the role of two sets of beliefs, the first of which involves illness beliefs include understandings of the nature of the illness, its severity, cause, timeframe, likely prognosis, and its 'treatability'. Illnesses that are seen as minor, short-term and likely to self-remit may result in less use of active treatments than conditions which are seen as long-term and likely to benefit from treatment. The second arm of this deliberation involves an evaluation of the costs and benefits of taking any medication. These include consideration of how likely the treatment is to cure the condition and how 'costly' this is likely to be. Cost here includes, but is not limited to, consideration of the likely side-effects of the medication. A summation of these benefits involves a measure of 'health threat' and' treatment necessity'. Michetti et al. (2017), for example, considered treatment beliefs in a group of individuals with serious immunological/inflammatory conditions and found illness threat (likely to continue forever and illness concerns) and treatment benefits (treatment necessity, treatment helping) to be key to adherence, and often more important than clinical parameters.

Applying this approach to a condition such as hypertension may explain why adherence to anti-hypertensive medication is so low. Many people believe hypertension to be a short-term condition. It is symptom-free, so it is not clear to the patient that it is present for much of the time. Accordingly, people prescribed such medication may not see the necessity to take any medication over a long period of time. Add in a number of side-effects associated with this type of medication, such as dizziness or light-headedness, dry mouth, constipation, drowsiness, headache and impotence, and the result is a scenario that involves patients taking medication for a condition they are not aware of having, which provides no obvious benefit, and which brings with it some unpleasant side-effects. Little wonder that adherence to such medication can be so low.

Interestingly, the Horne model may not hold in all circumstances. When a medical condition is severe, some patients may actually welcome a treatment that brings high levels of side-effects (Leventhal et al., 1986) as the lack of them can imply that the drug used is not sufficiently potent to cure their condition. Other factors may be quite idiosyncratic to the individual and condition. Gamble et al. (2007), for example, found that adherence to asthma medication was largely influenced by the fear of side-effects such as weight gain, anxiety, irritability and depression. However, participants also described feelings of ‘not being themselves’ and personality changes, resulting in a loss of their role within relationships when taking the medication. Kretchy, Owusu-Daaku and Danquah (2013) found spirituality was associated with poor adherence, while Jalal et al. (2019) found a belief that an illness was God’s will among Muslim patients was also predictive of poor adherence. Similarly, Jin and Acharya (2016) found beliefs about ying and yang determined adherence in people of Chinese descent living in the USA.

## It’s not just tablets

Many medical interventions require more significant behavioural change than taking medication, and it is to these we turn now. Measuring adherence to behavioural change programmes can be difficult. Measurement of daily diet, smoking or exercise levels is notoriously difficult to achieve accurately. However, one measure of adherence is relatively simple to measure accurately: whether patients attend clinics and other appointments. Here, the news is not good. Wolff et al.’s (2019) review, for example, of outpatient attendance of nearly 6,000 patients with chronic conditions over a two-year period revealed that 35 per cent of patients failed to attend at least one appointment related to their care. More demanding programmes typically have lower attendance rates. Only 56 per cent of the patients taking part in Jolly et al.’s (2007) cardiac rehabilitation programme considered in Chapter 17 ☛ attended five of 21 sessions. Similarly, Højskov et al. (2019) found that while 69 per cent of their cardiac rehabilitation patients took part in an exercise training programme while in hospital, only 47 per cent continued engagement once discharged home.

Smoking is one of the hardest behaviours to change, as a result of a number of factors including its addictive nature and the strong associations built up between smoking and various contexts such as feeling under stress and social occasions. Not surprisingly, therefore, adherence to medical advice to stop smoking is often low. Among patients with no evident illness, cessation rates of between 3 and 12 per cent have been found following advice to quit and provision of a leaflet (Unrod et al., 2007). The experience of illness may not improve cessation rates markedly. Schlyter et al. (2016), for example, found that 46 per cent of their sample of myocardial infarction patients were smoking at the time of the event. At two-year follow-up, 44 per cent were still smoking.

Changes in exercise levels may also be modest and reduce over time in both patient and non-patient populations. Lear et al. (2003) reported that few cardiac patients had achieved any changes on measures of leisure-time exercise and treadmill performance one year after a standard cardiac rehabilitation programme (see Chapter 17 ☛) which gave recommended exercise levels. Similarly, Bennett, Gruszczynska and Marke (2015) found the only changes in levels of exercise in the six months following a myocardial infarction were made by people already exercising at reasonably high levels who were likely to have minimal health advantage as a consequence. All other patients evidence no such change. In a more extended programme, involving monthly prompts to exercise and the provision of heart rate monitors and exercise diaries, Dolansky et al. (2010) reported that less than 37 per cent of their sample of cardiac patients adhered to a three-times-a-week exercise programme one year following attending a cardiac rehabilitation programme. Planned exercise programmes in sedentary individuals are also likely to have low attendance rates. In a review of the outcomes of family doctors prescribing attendance at group exercise programmes to sedentary but otherwise healthy individuals, Williams et al. (2007) reported that only between 12 and 42 per cent of those starting completed their 10–12-week programmes.

Adherence to recommended dietary recommendations is also modest. Enget Jensen et al. (2018), for example, found that only one quarter of their cohort of Norwegian women in the general population were adhering to the health food guidelines. In populations with restricted dietary and fluid intakes, such as people with kidney disease, adherence levels are remarkedly similar. Beerendrakumar, Ramamoorthy and Haridasan (2018), found that 89 per cent of the sample experienced a deviation from the recommended diet (20 per cent mild deviation; 69 per cent moderate) over a six-month period. To be fair to these individuals, the dietary requirements in kidney disease are particularly challenging, but the costs of non-adherence on their prognosis are also significant.

If required, achieving and maintaining dietary change is also not easy, both in patient populations and those people without evident disease. Leslie et al. (2004) found that 65 per cent of cardiac patients attending their dietary counselling programme achieved the target of five portions of fruit and vegetables per day. Only 31 per cent of their control group achieved this goal. However, the percentage of those eating healthily in the intervention group fell over a one-year follow-up period and did not differ from the control group by this time. Luszczynska and Cieslak (2009) found even lower levels of adherence in their cardiac patients: following rehabilitation, only 20 per cent were following recommended guidelines for fruit and vegetable intake, and this figure fell to 12 per cent at one-year follow-up.

Long-term interventions in healthy adults also show significant declines in adherence over time. An example of this can be found in a detailed study of a one-year behavioural weight-loss programme in healthy but overweight individuals reported by Acharya et al. (2009). They made weekly records of the percentage of overweight patients who attended their group sessions, monitored their food intake, set an exercise plan, and limited fat and calorie intake. In the first session after goals had been set, 90 per cent of the people attended the session, 82 per cent had adhered to the self-monitoring element, 72 per cent had exercised, while only 28 per cent had kept to the calorie and fat requirements. At the six-month mark, the respective percentages were 50 per cent (attendance), 45 per cent (self-monitor), 30 per cent (exercise and calorie target), and 20 per cent (fat intake). By one year, these figures had fallen to 50 per cent attendance, 25 per cent self-monitoring, 20 per cent calorie target and exercise, and 5 per cent fat intake. Overall, just as in adherence to medication, adherence to behavioural programmes is far below optimal, and may benefit from programmes designed to enhance them.

Reasons for poor or non-adherence vary considerably across behaviour and contexts. A number of studies have assessed non-adherence from an atheoretical perspective. Low adherence with the leg exercises and elevation required in the treatment of leg ulcer, for example, was found to be associated with pain, discomfort and lack of clarity concerning what exercises and other precautionary behaviours patients could engage in to improve their ulcers (Van Hecke et al., 2009). A study of Kuwaiti patients (Serour et al., 2007) at high risk of cardiac disease revealed some interesting and culturally idiosyncratic reasons for non-adherence to a number of lifestyle changes. The main predictors of non-adherence to a low-fat diet were lack of motivation, difficulties in adhering to a diet different to that of the rest of the family, and social gatherings. The main barriers to adherence to exercise were lack of time, coexisting diseases, and adverse weather conditions (presumably heat, not rain!). Factors influencing adherence to lifestyle measures in general were the high fat and calorie content of traditional Kuwaiti food, stress, a high consumption of fast food, high frequency of social gatherings, an ‘abundance of maids’, and excessive use of cars!

One key issue of relevance is that of motivation, or lack of motivation, and competing demands on time. In the context of exercise, for example, both Jones et al. (2007) in cardiac patients and Casey et al. (2010) in people with type 2 diabetes, found this to be the primary reason for non-adherence. Both found that the presence of other health problems also impacted on engagement with the exercise programme. Family and social support, whether from friends or professionals, are also important factors. In the context of diet, Luszczynska and Cieslak (2009) found that intake of fruit and vegetables in cardiac patients was predicted by the presence of family support, while the type 2 diabetics of Casey et al. (2010) appreciated the monitoring, encouragement and accountability provided by programme staff, and when this was withdrawn frequently reduced the levels of exercise they took. From a series of qualitative studies, Huberty et al. (2008) found that the key factors associated with continuing physical activity following completion of a structured exercise programme were participants' self-worth, motivation, activity enjoyment, priorities, body image, ability to access support, and self-regulation skills such as planning and/or coping with obstacles to exercise and so on.

From a more theoretical perspective, the illness perceptions model of Leventhal or Horne's extension of this model also appear relevant to prescribed behavioural change. MacInnes (2013), for example, found that 46 per cent of the variance in self-care of patients with heart failure was predicted by their illness representations and treatment beliefs. Bourbeau and Bartlett (2008) found adherence to exercises to improve lung function and smoking cessation in patients with COPD were predicted by their perceptions of the disease, their confidence in their ability to control their health, and anticipating serious consequences should they not adhere to the treatment programme. In the context of adhering to appropriate self-care behaviours such as taking medication, meal planning, regular exercise, and testing blood glucose by type 2 diabetics (see Chapter 8 ☛), Daly et al. (2009) found that key predictors of adherence to an appropriate regime were cost, the belief that diabetes was a serious problem, being married, and greater self-reported satisfaction linked to taking medication and testing blood glucose. Depression was independently predictive of non-adherence.

More extended theoretical models may also be useful in this context. In a review of the psychological factors that contributed to adherence to exercise programmes by cardiac patients, Petter et al. (2009) found the most consistent predictors were: confidence in the ability to exercise (including dealing with obstacles to exercise and other indirect issues), intentions to exercise, perceived control over exercise, belief in the benefits of previous physical activity, perceived barriers to exercise, and action planning, all of which fall within the self-regulation (Leventhal et al., 1992) or Health Action Process models discussed in Chapters 5 and 9 ☛ (see Sniehotta, 2009).

## Maximising adherence to medication

The chances of an individual taking the medication they are prescribed can be increased by a few simple strategies within the consultation.

### Achieving concordance

One key factor that may increase adherence to a recommended regimen is that both patient and prescriber have discussed the various treatment options and agreed to follow a treatment regimen. The discussion of shared decision making earlier in this chapter provided an outline of the steps within the consultation that will lead to shared decisions/concordance between doctor and patient. A number of factors that enhance this process can also be identified from the previous discussion, including the doctor providing relevant information in a language understandable to the patient, and the doctor listening and responding to the patient in ways that encourage engagement in the decision-making process. Concordance is unlikely to be achieved by health professionals who adopt a strong biomedical stance within the consultation and who pay little regard for the social and emotional concerns that patients may bring to the consultation. The NICE guidelines (2009a) outline a number of communication issues that can influence this process. Their recommendations include the following:

Involvement in decision making:

- Offer all patients the opportunity to be involved in making decisions about prescribed medicines. Establish what level of involvement in decision-making the patient would like.
- Discuss with the patient why they might benefit from the treatment. Clearly explain the disease or condition and how the medicine will influence this.
- Explain the medical aims of the treatment to patients and openly discuss the pros and cons of proposed medicines. The discussion should be at the level preferred by the patient.
- Avoid making assumptions about patient preferences about treatment. Talk to the patient to find out their preferences and note any non-verbal cues that may indicate you need to explore the patient's perspective further.
- Accept that patients may have different views from healthcare professionals about the balance of risks, benefits and side effects of medicines.
- Be aware that increasing patient involvement may mean that the patient decides not to take or to stop taking a medicine. Accept that the patient has the right to decide not to take a medicine, even if you do not agree

with the decision, as long as the patient has the capacity to make an informed decision and has been provided with the information needed to make such a decision.

Beliefs about medicine:

- Be aware that patients' concerns about medicines, and whether they believe they need them, affect how and whether they take their prescribed medicines.
- Ask patients what they know, believe and understand about medicines before prescribing new treatments and when reviewing medicines.
- Ask if the patient has any specific concerns about their medicines, whenever you prescribe, dispense or review medicines. These may include concerns about becoming dependent on medicines and concerns about adverse effects. Address these concerns.

In the context of this collaborative approach, a number of more specific interventions may be of benefit.

### Patient decision aids

One contributor to low adherence to medication has been identified as low motivation to take medication due to a poor understanding of the benefits and costs of any treatment; in terms of disease characteristics, as well as the benefits and disbenefits of taking medication (see the earlier Horne and Weinman model). Patient decision aids provide a mechanism for allowing more informed patient choice based on appropriate knowledge. They can involve written or pictographic information provided through pamphlets, videos, or web-based tools. Importantly, although these may improve patient decision making and reduce ambivalence in relation to treatment, they may not always increase adherence: as noted in the NICE guidelines, information can influence decisions, but not always towards the optimal medical treatment. Other factors, such as low perceived benefit, and high costs, such as side effects may also come into play. In their review of this issue, Stacey et al. (2017) considered evidence from 115 studies involving 34,444 participants. The benefits of this approach were less than optimal. The found decision aids were beneficial in choosing to initiate cardiac medication and not taking unnecessary antibiotics, while choices of a range of other medications were unaltered. On measures of longer-term adherence following these choices, only 16 studies addressed this issue. Of these, four found a benefit following use of a simple decision aid at six-months following initiation, while the other studies found no benefit.

| Frequently asked questions | Lumpectomy with radiotherapy | Mastectomy |
|---|---|---|
| Which surgery is best for long term survival? | There is no difference between surgery options | There is no difference between surgery options |
| What are the chances of cancer coming back in the breast? | Breast cancer will come back in the breast in about 10 in 100 women in the 10 years after a lumpectomy | Breast cancer will come back in the area of the scar in about 5 in 100 women in the 10 years after a mastectomy |
| What is removed? | The cancer lump is removed with a margin of tissue | The whole breast is removed |
| Will I need more than one operation on the breast? | Possibly, if cancer cells remain in the breast after the lumpectomy. This can occur in up to 5 in 100 women | No, unless you choose breast reconstruction |
| How long will it take to recover? | Most women are home 24 hours after surgery | Most women are home 2-3 days after surgery |
| Will I need radiotherapy? | Yes, for up to 6 weeks after surgery | Unlikely, radiotherapy is not routine after mastecomy |
| Will I need to have my lymph glands removed? | Some or all of the lymph glands in the armpit are usually removed | Some or all of the lymph glands in the armpit are usually removed |
| Will I need chemotherapy? | Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy | Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy |
| Will I lose my hair? | Hair loss is common after chemotherapy | Hair loss is common after chemotherapy |

**Figure 10.2** Examples of information provided in a decision aid to encourage discussion of treatment options for breast cancer

### Maximising memory at the time of prescription

Memory for information given in consultations is often surprisingly poor. A classic summation of the evidence by Ley (1997) suggested that 75 per cent of information given in four statements is likely to be retained: only

50 per cent of information given in ten statements will be retained. One simple strategy involves giving information in a structured manner. According to Ley, the most important information should be given early or late in the flow of information to maximise primacy and recency effects and its importance should be emphasised. Further strategies include repetition and the use of specific rather than general statements. This may be augmented by asking patients to repeat key messages during the consultation to ensure understanding and increase memory consolidation. In addition to this structured approach information can also be given in a more permanent form. Stephens et al. (2008), for example, provided patients who had oesophageal cancer with a tape recording of the consultation in which they were given their diagnosis. Patients in this group were more likely to retain information given in the consultation.

When information is given in written form, many people read it: Nathan et al. (2007), for example, found that 70 per cent of patients read patient-information leaflets when given new medication. Of course, written information should take into account the same issues as those that relate to spoken information – it needs to be clear, jargon-free, and not so complex that readers will be unable to understand it. Unfortunately, this requirement is not always met. Freda (2005) found that 41 of 74 patient-education brochures produced by the American Academy of Pediatrics had readability levels beyond the majority of their readers. Even innovative approaches such as the use of pictograms in addition to text to help people with limited literacy skills may not be as helpful as intended. Knapp et al. (2005), for example, found that only 30 per cent of pictograms used in medication leaflets were understood by 85 per cent of the population. In addition, although memory may improve following appropriate information provision, this may not necessarily improve adherence. Studies that have been conducted exploring this issue have found little or no differences in adherence following even good education or providing information on their own (Costa et al., 2015). Any such intervention is best combined with additional strategies, although even these may have limited impact.

### Longer-term memory strategies

Perhaps the simplest methods to enhance adherence involve ensuring that the prescribed medical regimen places as little demand on memory as possible. Nachega et al. (2010), for example, noted significant increases in adherence and measures of viral load in people with HIV whose HAART regimen (see Chapter 8 ☛) was simplified to one tablet a day. Other approaches involve helping patients to select contextual cues to help them remember to take medication (take with food or other daily routines) or placing medicine in plastic medication boxes with compartments that are filled with the tablets to be taken at each time during the week. These are often used by older people and can be filled by health-care professionals or family members. More complex procedures involve the use of reminders sent via the post, text, or telephone. Adler et al. (2017) reviewed the research in relation to texting reminders to take medication to reduce risk of a further cardiovascular event. The impact was significant, with one paper (admittedly the strongest finding) reporting a four-fold difference in adherence between participants who did and who did not receive the texts.

More complex interventions may use a combination of factors to trigger memories to take medication and to act on these memories. Insel et al. (2016), for example, developed an intervention designed to increase medication use by older adults who were less than 90 per cent adherent to a range of medication regimens. In this, participants were helped to identify a range of factors that would remind them to take their medication, including mentally rehearsing taking medication, establishing a medication routine, identifying cues associated with taking medication which would trigger its use, planning to act on these cues immediately, and using a medication organiser. This relatively complex routine achieved significant gains in the period immediately following the intervention, achieving increases in adherence from an average of 57 to 78 per cent (compared to no change in a control condition). However, most of the immediate gains achieved were lost over the following five months.

**RESEARCH FOCUS**

## Does a smartphone app increase adherence to medication following cardiac surgery?

Yu, C., Liu, C., Du, J., Liu, H … . MISSION-2 Collaborative Group (2020). Smartphone-based application to improve medication adherence in patients after surgical coronary revascularization. *American Heart Journal*, 228: 17–26.

The authors of this Chinese study noted that secondary prevention (e.g., preventing further disease progression and complications of surgery) is important following cardiac surgery know as coronary artery bypass grafting (CABG), but that adherence to the medication regime required can be poor. They therefore set out to determine whether an intervention using a smartphone app could be of benefit in increasing adherence.

### Method

#### *Participants*

Participants were recruited from four hospitals serving diverse cultural and socio-economic regions across China. They were eligible to take part in the study if they underwent CABG, were over 18 years, and prescribed at least one secondary preventive oral medication within two weeks of surgery. In addition, they needed access to a smartphone and to be able to operate at least three applications on it.

#### *Outcome measures*

Measures were taken at baseline, three- and six-month follow-up. Primary outcomes were based around adherence:

- *Morisky Medication Adherence Scale*: an eight-item self-report measure of adherence. This provides scores indicating both intentional and unintentional adherence (forgetting). Low adherence indicated by an overall score of <6.
- *Log of responses indicating medication use*: based on responses to medication reminders on the app – see below.

Secondary outcomes included:

- *Medical data (MACCE; Major Adverse Cardiovascular and Cerebrovascular Events):* mortality, major cardiac events, cardiac-related rehospitalisations, and stroke.
- *Health indicators*: blood pressure, BMI and self-report smoking status.

#### *Randomisation and intervention*

Participants were randomly allocated to either a smartphone application intervention group or usual care control. The smartphone application (known as the Heart Health Application) was developed after a number of prototypes were piloted to maximise the user experience and likely use, and comprised four modules:

(i) medication reminders and a click box to indicate when the required medication was taken;
(ii) cardiac health education that could be read at any time;
(iii) health questionnaire and links to medication and secondary prevention goals followed by personalised;
(iv) feedback on their latest cardiac risk characteristics, including, for example, cholesterol levels.

### Results

One thousand patients (mean age 57.28 [SD, 9.09] years; 85 per cent males) were entered into the study over a one-year period. By the end of the study follow-up, 987 remained in the study. At baseline, there were no significant differences between the two conditions on any of the measures, including demographics, medical measures, smoking, or health indicator measures.

By three-month follow-up, 5.8 per cent and 6.3 per cent (RR = 1.080, 95% CI 0.641-1.822, *P* = .791) of participants in the control group and intervention group respectively had scores on the MMAS indicating significant non-adherence. By six-month follow-up, levels of non-adherence were higher (11.8 and

11.7 per cent; but again, did not differ according to the condition into which participants were randomised (RR = 1.005, 95% CI 0.682-1.480, *P* = 1.000). Mean scores on the MMAS also did not differ at this time: mean difference 0.052, 95CI -0.087 to 0.191, *p* = .460. The same pattern of results was found for both sub-scales measuring intentional and unintentional non-adherence.

A similar lack of between condition differences was found on all other, secondary, measures. Perhaps the reasons for this lack of affect can be found in process measures involving rates of use and more descriptive feedback. Rates of use of, and particularly response to, the app began at a high (88 per cent) level one month following its use, and fell consistently through the duration of the study, with usage by only 42.5 per cent of users at two-month follow-up and 9.2 per cent usage at six-month follow-up. Rates of actually responding to the app were as low as 34 percent at one month-follow up and 7.7 per cent at six months.

Of the 501 participants in the intervention group, 379 (75.6 per cent) submitted feedback on their use of the app. This indicated that only 17.4 per cent used the application every day, while 44.6 per cent 'often' forgot to use it. Only 15 per cent of participants thought the application was 'very useful', while more than half thought the application was of 'little use' or 'useless'.

## Discussion

This was a well-powered study with exactly 1,000 participants, although the number of low adherent participants at whom the study was targeted formed only a relatively small sub-group within this larger cohort. The study may therefore have less statistical power than may be immediately thought. Nevertheless, the differences between the app intervention and usual care condition were minimal, and essentially non-existent. To put it bluntly, the app was not valued by the majority of its recipients and did not change behaviour. The authors suggest this dissatisfaction may have been a consequence of many software glitches and incompatibilities encountered by the app users. They also note that some form of incentive programme attached to the app may have increased adherence. Perhaps the key take home message from the study is that changing adherence is not easy, and what appears to be a simple (to the receiver) intervention requiring minimal effort by its recipients still struggles to achieve change. Additional piloting from both a user and technical perspective may have been beneficial, but this is not guaranteed.

### Incentives and social support

If memory aids and the intrinsic gains of better disease control are of at best modest benefit, does it help to provide extrinsic rewards for taking medication? Considering this issue, Volpp et al. (2017) evaluated the effect of a range of interventions including financial incentives (participation in a daily lottery) and social support in increasing adherence following a myocardial infarction (see Chapter 8 ☛). The effectiveness of their intervention was measured using electronic counters in the pill bottles, which transmitted a signal every time the bottles were opened to avoid bias in self-report medication. Participants had the option of setting up an automatic notification to a friend or family member if the bottles were not used in two of the three previous days. No differences were found between this quite complex intervention and a standard treatment control. In an even more financially extravagant intervention, Asch et al. (2015) found that neither paying (up to over $1,000 per patient) doctors to enrol patients into a medication programme and ensure patients achieved a target cholesterol level nor entering patients into a lottery if they achieved them were sufficient incentive to improve adherence beyond a control condition. It seems it is surprisingly difficult to encourage people to take their medication.

## Case history: Mr F

Many older adults fail to take their medication at appropriate times or forget to take it at all. As noted in the main text this may be because of the complexity of their medication regime, rather than failing memory. But where memory is fading adherence to appropriate medication regimens may become particularly problematic and responsibility for this may fall to others rather than the individual involved. Mr F was one such person who at the age of 73 years had a variety of health problems, many of which may well have contributed to

**Photo 10.3** A pill organiser that can be used to facilitate adherence to complex medical regimens

*Source*: Guzel Studio/Shutterstock.

his failing memory, but all of which required appropriate medication dosage. His tablets included treatment for rheumatoid arthritis using painkillers and non-steroidal anti-inflammatory medication, high blood pressure using anti-hypertensive medication, and type 2 diabetes using tablets to lower his blood sugar levels. Importantly, with this not unusual combination of medical problems, Mr F was taking a carefully prescribed medication regimen that was designed to maximise its effectiveness while avoiding problematic combinations of drugs that may have had a serious impact on his health.

Neither Mr F nor his wife proved effective in adhering or ensuring adherence to his medication regimen and he was increasingly affected by painful joints, which restricted the activity he should have been engaging in to help his diabetes. Regular check-ups with his doctor revealed that his blood pressure was much higher than it should have been, and his visiting nurse regularly found higher blood sugar levels than were ideal. Clear labelling of bottles, written instructions when each tablet should be taken, and repeat visits by a district nurse had failed to improve or his wife's adherence to his medication regimen. The nurse therefore initiated a simple, but highly effective approach that did prove of benefit: the use of a pill organiser (see Photo 10.3). The timing of his medication was simplified to either morning or evening. Then, his district nurse visited the home each week and placed the relevant medication in each box within the organiser. The organiser was then kept on display in an obvious position in the kitchen to ensure it was seen and acted as a cue to take medication. With this regimen, neither Mr F nor his wife had to remember which drugs were taken at any one time. He simply took the drugs in each box at the time stipulated. The nurse who set the scheme up visited each day at the beginning of his use of the pill organiser to check all was well, and then visited briefly each week to refill it. As a consequence, Mr F did not experience a 'miracle cure', but his blood pressure and blood glucose levels did fall significantly, reducing his risk of further medical complications.

## SUMMARY

The chapter has reviewed a number of issues related to how health professionals interact with patients, and how this can influence the outcome of any treatment they may recommend.

1. There has been a shift from the paternal ‘doctor knows best’ type of consultation to more patient-centred approaches, and the ultimate outcome of this shift – shared decision making. It was noted that while this has many benefits, many patients are cautious in adopting it, as it raises concerns over the apparent expertise of health professionals and may place a responsibility on patients for their treatment that they are unwilling to carry.
2. Some other elements of the consultation that may influence its outcome, including:
    - the gender of the health professional – women appear more empathic and caring, factors usually associated with greater satisfaction with the interview;
    - the ‘spin’ given to information;
    - the input of the patient: people who ask more questions tend to gain more information from the consultation.
3. Breaking bad news involves telling patients that they have a serious illness, and that they may die from it. It is a stressful process for both patient and health professional. Key factors in optimising this process include:
    - Give the news in person, in private, with enough time and without interruptions.
    - Find out what the patient knows about their diagnosis.
    - Find out what the patient wants to know.
    - Share the information, starting with a ‘warning shot’.
    - Respond to the patient’s feelings.
    - Plan and follow through.
4. Medical decision making can be influenced by a number of factors. Doctors often employ heuristics to help them arrive at a diagnosis. This can speed the process up, but increases the risk of diagnostic errors. Typical errors are those of:
    - availability;
    - representativeness;
    - differing pay-offs of differing diagnoses.
5. Adherence to recommended medical treatments is influenced by a number of factors, including:
    - social factors;
    - psychological factors;
    - treatment factors;
    - family dynamics;
    - beliefs about the nature of the illness and its treatment regimen.
6. Adherence may be enhanced by:
    - the use of patient-centred approaches and shared decision making;
    - maximising satisfaction with the process of treatment;
    - maximising understanding of the condition and its treatment;
    - maximising memory for information given.
7. Beyond the consultation, these factors may be added to be a number of strategies, including:
    - convenient timing of drug taking;
    - relevant information;
    - reminders to take medications;
    - self-monitoring (i.e. noting down when and where medication is taken);
    - reinforcement of appropriate use of medication.
8. Adherence to behavioural programmes is also far from maximal. This may result from a variety of factors, including cost–benefit analysis of change, low motivation, and difficulties in planning or executing consistent change. Key theoretical variables associated with adherence to behavioural programmes are:
    - confidence in the ability to exercise;
    - intentions to exercise;
    - perceived control over exercise;
    - belief in the benefits of previous physical activity;
    - perceived barriers to exercise;
    - action planning.
9. Self-regulation-based interventions that take these factors into account appear to be the most effective means of achieving sustained behavioural change.

## Further reading

Here are a number of reviews of issues dealt with in the chapter. Most of them are 'as it says on the tin', in that the title shows the content of the paper.

Röttele, N., Schöpf-Lazzarino, A.C., Becker, S. et al. (2020). Agreement of physician and patient ratings of communication in medical encounters: a systematic review and meta-analysis of interrater agreement. *Patient Education and Counseling*, 10: 1873–1882.

Review showing the profound differences between doctors' and patients' views on communication during consultations.

Wan, M., Luo, X., Wang, J. et al. (2020). The impact on quality of life from informing diagnosis in patients with cancer: a systematic review and meta-analysis. *BMC Cancer*, 20: 618.

One of the questions asked in the chapter was whether or not we should tell patients of a poor prognosis. This paper provides the answer.

Coughlan, J.J., Mullins, C.F. and Kiernan, T.J. (2020). Diagnosing, fast and slow. *Postgraduate Medical Journal*, postgradmedj-2019-137412.

Nice non-technical review of the role of heuristics in medical decision making.

Elwyn G., Durand M.A., Song J. et al. (2017). A three-talk model for shared decision making: multistage consultation process. *British Medical Journal*, 359: j4891.

The latest shared decision-making model by one the leading UK researchers in shared decision making.

Cross, A.J., Elliott, R.A., Petrie, K., et al. (2020). Interventions for improving medication-taking ability and adherence in older adults prescribed multiple medications. *The Cochrane Database of Systematic Reviews*, *5*: CD012419.

Review of the effectiveness of simplification of medication regimens on adherence in older adults.

WEB

Visit the website at **go.pearson.com/uk/he/resources** for additional resources to help you with your study.

# Chapter 11

# Stress, health and illness: theory

## Learning outcomes

By the end of this chapter, you should have an understanding of:

- stress as a stimulus (stressors)
- stress as a result of an interaction between an event and an individual
- the critical role of cognitive appraisal
- the nature of acute and chronic stress
- physiological processes invoked by the stress experience
- how stress manifests itself in various diseases

## Sleep (or lack of it) in a time of COVID-19

An important marker of, and contributor, to stress is the amount and quality of sleep we experience. Even in ‘normal’ times, many people find their sleep is disturbed and limited in its duration. Rumination about events of the day, worry about tomorrow’s plans and concerns all impact on our sleep, as well as too frequent engagement with emails and social media on phones and tablets that serve to keep us awake either by triggering worrying thought patterns or simply the type of light they emit. This background level of sleep disturbance has been accentuated by the experience of the COVID-19 pandemic. A review in the Lancet (Partinen, 2021) showed that the year 2020 was associated with significant increases in sleep disturbance around the world. In Italy, for example, over half (57 per cent) the respondents in a large population survey reported poor sleep quality, while 32 per cent reported high levels of anxiety, 42 per cent reported high distress and 8 per cent reported post-traumatic symptoms. Of particular note are the findings of the COVID-19 Sleep Study (Partinen et al., 2001), which identified that symptoms of fatigue, sleepiness and REM sleep behaviour disorders were particularly associated with concerns or the experience of COVID-19 infection, while general insomnia was related to the experience of confinement, coping with changes in work schedules and requirements, the stress of home childcare and schooling, and the limitations in levels of physical exercise and social interaction. Poor sleep and the experience of nightmares have become a key feature of the COVID-19 pandemic, acting as markers for a wider stress response experienced by significant proportion of the population even in the absence of COVID-19 infection.

This chapter and Chapter 12 ☛ consider what factors contribute to events being described and experienced as ‘stressful’, and highlights how thoughts and appraisals of events can have a range of negative consequences for health and wellbeing, via effects on coping responses and behaviours, but also on physiological systems.

## Chapter outline

**The beginning of this chapter outlines the main thinking about stress in terms of nature and definition, and highlights three main ways in which stress is studied: as a stimulus, as a transaction between a stimulus event and an individual's appraisal of it, and as a biological and physiological response. The second of these reflects a psychological model of stress proposed by Richard Lazarus and his colleagues and is described in detail to illustrate the central role of cognitive appraisal. This is done by examining how stress impacts upon us all in our living and working lives, and by examining acute and chronic stressors. The final part of the chapter provides evidence as to the physiological processes by which stress and our responses to it exert an influence on physical health, focusing particularly, but not solely, on cancer, CHD and HIV. By the end of the chapter, the nature of stress and the processes by which it may impact on illness should be clear.**

# Concepts of stress

The term 'stress' is used very widely and with several meanings: everyone probably thinks they know what the term means, but few people define it in exactly the same way. Stress has generally been examined in one of three ways: as a stimulus or event external to the individual; as a psychological transaction between the stimulus event and the cognitive and emotional characteristics of the individual; or as a physical or biological reaction. Each of these perspectives and their accompanying methodologies have their own strengths and weaknesses, which are outlined in the forthcoming sections. It is worth noting however that imprecision in definition and measurement, coupled with the heterogeneity of what constitutes 'stress', as you will see below in terms of biological and psychosocial perspectives and considerations, has contributed to challenges in integrating or synthesising research findings (Kagan, 2016).

### WHAT DO YOU THINK?

What does stress mean to you? What causes you to feel stressed?

Think of some recent events that you have experienced as stressful. Why was this? Reflect on your answers to these questions as the chapter progresses.

## Stress as a stimulus

In thinking of stress as a stimulus, researchers focus on stressful events involving the external environment: i.e. a person will attribute their tension to an event or events such as moving house or getting married. The event and its properties are considered amenable to objective definition and measurement: for example, the event can be labelled (e.g. wedding) and aspects of it such as its proximity (e.g. next week, next year) can be assessed. Researchers taking this approach have studied the impact of a wide variety of stressors on individuals or groups, including catastrophic events such as earthquakes, floods or plane crashes, and, more commonly, major life events such as losing or starting a job, getting married or divorced, giving birth, being bereaved, or even going on holiday. Life events such as these are considered to require significant adjustment on the part of the person experiencing them and can include both positive and negative events.

## Life events theory

The major proponents of this approach were Holmes and Rahe, who in 1967 proposed their **life events** theory. They proposed that naturally occurring life events did not simply have unitary consequences for a person but cumulative effects; in other words, the more life events one experienced, for example within the past year, the greater the likelihood of physical health problems. Furthermore, they claimed that specific kinds of event could be weighted against each other. To justify these claims, Holmes and Rahe had carried out a series of interesting studies. First, they invited over 5,000 participants to generate a list of events they found most stressful. From this, they generated a representative list of 43 commonly mentioned events, including positive, negative, frequent and rare events. Holmes and Rahe then asked a new sample of almost 400 people to rank the listed events in order of the degree of disruption the event, if experienced, had caused them. Finally, they asked participants to rate each event against marriage, which had arbitrarily been given a value of 500 by the researchers. For example, if a participant considered divorce as requiring twice as much adjustment as marriage, it was given a value of 1,000. By averaging the ratings received for each event item and then ranking them, Holmes and Rahe produced a scale known as the Social Readjustment Rating Scale (SRRS; Holmes and Rahe, 1967; see Table 11.1), with values ranging from 11 (minor violations of law) to a highest score of 100 (assigned to death of a spouse). The values were called life change units (LCU). Social readjustment was defined as 'the intensity and length of time necessary to accommodate to a life event, *regardless of the desirability of this event*' (Holmes and Masuda, 1974: 49), highlighting the fact that both positive (e.g. marriage) and negative events (e.g. redundancy) would require some adjustment on the part of the individual. A subsequent study of 88 physicians (Rahe, 1974) found that the greater the LCU score the higher the risk of ill-health. Of the 96 major health changes reported by the participants, 89 took place in individuals scoring over 150 LCUs; and when LCU scores exceeded 300, over 70 per cent of the physicians reported subsequent ill health. Those individuals scoring less than 150 LCUs tended to report good health. Holmes and Masuda (1974) defined a *mild life crisis* as scoring between 150 and 199 LCUs, a *moderate life crisis* as scoring between 200 and 299 and a *major life crisis* as scoring over 300. They drew not only on their own work but also on that of other researchers of the time to support their hypothesis that life change could cause ill health (see review by Tennant, 2002). For example, more recently, Lorenz et al. (2006) found negative health impacts of divorce upon women divorcees both in the short term but also in the decade following, Feldman et al. (2007)

**life events**

a term used to describe occurrences in a person's life which may be viewed positively or negatively but which inherently require some adjustment on the part of the person (e.g. marriage, loss of job). Such events are implicated in the experience of stress.

**Table 11.1** Representative life event items from the social readjustment rating scale and their LCUs

| Event | LCU rating (1–100) |
|---|---|
| Death of a spouse | 100 |
| Divorce | 75 |
| Death of a close family member | 63 |
| Personal injury or illness | 53 |
| Marriage | 50 |
| Being fired from work | 47 |
| Retirement | 45 |
| Sex difficulties | 39 |
| Death of a close friend | 37 |
| Change to a different job | 36 |
| Foreclosure of mortgage or loan | 30 |
| Son or daughter leaving home | 29 |
| Outstanding personal achievement | 28 |
| Begin or end school | 26 |
| Trouble with boss | 23 |
| Change in residence | 20 |
| Change in social activities | 18 |
| Vacation | 13 |
| Christmas | 12 |

*Source*: Holmes and Rahe (1967).

report health consequences of stress, prejudice and change experienced by refugees in the Netherlands.

## Limitations of life events measurement

The evidence of the associations between LCUs and ill health (physical and/or mental) has been questioned as a result of various methodological or sampling limitations. For example:

- Many studies reporting moderate to strong associations between LCUs, health and illness (including many of Holmes and colleagues') relied on retrospective assessment: i.e. participants who were already ill were asked to report whether or not they had experienced any life events prior to the onset of illness. We know (see Chapter 14 ☛) that ill people search for explanations for illness, which may include misattributions to past events. Studies employing prospective designs found much weaker or non-existent relationships.
- Items included in the scale are not globally appropriate, nor commonplace. For example, depending on your age, many of the listed events may not be applicable (divorce, childbirth, etc.) Some of the listed events may simply not occur with sufficient frequency to enable many individuals to report them or for their effects on health to be experienced (e.g. moving house).
- Items may be intertwined/interrelated and may cancel out or enhance the effects of one another (for example, marriage requires positive adjustments but may coincide with a negatively perceived house move).
- Some of the listed events are vague and ambiguous: for example, reporting a 'change in social activities' could mean many things brought about for many different reasons, from taking up dancing with a new partner, to not being allowed to socialise during the COVID-19 pandemic.
- Allocating LCUs to events assumes that all people rank events in a similar way. However, as psychologists, we know this is unlikely! Think of moving house. For some people this will be the desired outcome of increased financial resources, while for others it will be the unwanted consequence of repossession by a bank following prolonged failure to pay a mortgage.

Finally, inconsistencies have been reported between events rated as 'severe' using the checklist approach, but then not rated as severe in a subsequent interview (Brown and Harris, 1989), raising questions about the SRRS's reliability. Addressing this, Brown and Harris developed a more rigorous approach using the LEDS (Life Events and Difficulties Scale) in a semi-structured interview carried out by a trained interviewer. Interviews were recorded and then events described to an independent rater along with details of the individual's biography and context. The rater then rated the events on the basis of its severity in terms of 'threat' or 'loss' and the event's context, but without any emotional inference.

In spite of many measurement limitations, major life events can and do impact on people's lives, whatever their age. For example, children experiencing stressful life events have been found to show increased fear emotions in the future, suggesting a future social influence of stress experiences (Laceulle et al., 2014). As well as the number of events experienced, the 'type of event' is also important. For example, health-related life events (for example, receiving a serious illness diagnosis, having an operation) significantly predicted mortality among a middle-aged sample followed for 17 years even after controlling for other risk factors such as sex, BMI, systolic blood pressure, heart disease, and occupational status, whereas health-unrelated life events, such as moving house or divorce, were not predictive (Phillips et al., 2008). Many prospective longitudinal studies now assess the frequency and nature of life event experience of study samples on the basis also that life events may influence other variables of interest: for example, adjustment to disability may be undermined by the occurrence of other major life changes.

### Life hassles

In addition to major and often rare life events, research has also highlighted the stressful nature of daily hassles. Kanner et al. (1981: 3) defined hassles as 'irritating, frustrating, distressing demands that to some degree characterize everyday transactions with the environment' and included such things as not having enough money for food or clothing, losing things, being overloaded with responsibilities, making silly practical mistakes, or having a row with a partner. Unlike major life events, hassles do not generally require major adjustment on the part of the person experiencing them, but their impact was thought to be particularly evident if they were frequent, chronic or repeated over a particular period of time. These hypotheses have been frequently confirmed. In one relevant study, for example, Tran et al. (2020) conducted a longitudinal study of students in their first year of college, focusing on the reciprocal impact of hassles and health complaints. They found evidence that the frequency of daily hassles, measured using daily diaries, was predictive of subsequent levels of health complaints, but that health complaints did not predict levels of hassles. In another longitudinal study, Serido, Almeida and Wethington (2004) found both separate and independent direct impacts of chronic stressors and daily hassles on measures of psychological distress, and that chronic stress also moderated the impact of daily stressors, with people experiencing high levels of hassles and chronic stress having the worst mental wellbeing.

By contrast, the role of positively rated events, described as ‘uplifts’ (e.g., ‘getting away’ with something, completing a task, getting or giving a compliment, having a laugh) were acknowledged more thoroughly in those taking a ‘hassles’ approach than in life events theory. Kanner found effects of life stage/role and gender on how both hassles and uplifts were perceived and appraised. Middle-aged individuals, professionals, and students, for example, were found to differ in the importance they attached to particular events, in particular economic concerns, work and time pressures, and social hassles. In terms of uplifts, the groups differed in their weighting of having good health, spending time with family, and hedonistic items such as socialising and having fun. A more recent qualitative study showed emphasised the important ‘balancing of negatives and positives’ in determining overall stress. Judd, Dorozenko and Breen (2017) looked at work stresses experienced by healthcare workers involved in caring for people with disabilities and found a trade-off between stresses such as the physically demanding nature of their work, earning a low income, and limited decision making with the rewards of seeing a client develop new skills or being shown appreciation for their work. The absence of uplifts was associated with occupational burnout.

This finding that uplifts can moderate the negative impact of hassles is consistent with both stress theory and positive psychology theory in which the experience of positive emotions (a likely consequence of experiencing an uplift such as receiving a compliment, getting a good grade) enhances coping appraisals (e.g. Larsson et al., 2020; Fredrickson, 2001, 2013; Folkman, 2008). However, the evidence for this is inconclusive, as few studies explore the prospective interactions between positive and negative events. For example, in one study of schoolchildren, only a weak association existed between hassles and uplifts, and uplifts were only weakly associated with mental health outcomes (Barrett and Heubeck, 2000). It is also worth noting that most studies of stress have been conducted with adults, and most stress assessments have been developed with adult populations, in part due to concerns about the language competence of particularly young children. However, Valentine (2010) demonstrated that the majority (78 per cent) of schoolchildren aged 4–11 knew the word stress, and this increased with age, from 45 per cent of the 4–5-year-olds, to 62 per cent of the 6–7-year-olds and up to 100 per cent of those aged 8 or more. Although this study included a relatively small sample (50 children ranging from 4–11 years old), the finding that children have a stress concept, which becomes increasingly complex with age is important. The challenge of friendships and ‘fitting in’, being separated from parents (particularly in younger children), balancing school demands of continuous assessment with social interests and the increasing expectations placed on children, all contribute to stress, as do the child’s response to family events – household tensions are picked up on by a child, such as moving home, parental unemployment, financial pressures and, increasingly, parental divorce. A child’s coping response when faced with stress are important to their health and behavioural outcomes, to their future ability to cope and even to their future outlook on life. We perhaps need updated measures to incorporate modern pressures such as those emerging from social network usage and incidences of cyber bullying (e.g. Chapin, 2014). For more detailed consideration of issues related to child stress concepts and measurement challenges more generally, see Turner-Cobb (2014).

If health outcomes are indeed affected by major events or an accumulation of minor events, what are the processes (psychophysiological or behavioural) by which this occurs? To answer the ‘how’ question leads us to consider physiological theories of stress (stress manifest in biological responses, see later section), whereas to answer the ‘why’ question requires consideration of sociological explanations (see, in part, Chapter 2 ☛ discussion of social inequalities in health) and psychological theories of stress involving cognitive appraisal and emotion. We turn here to the psychological explanations.

## Stress as a transaction

According to psychological theory, stress is a subjective experience, an internal state of being that may or may not be considered by an outside observer as being appropriate to the situation that evoked the response. As John Milton (1608–74) put it when he wrote Paradise Lost: ‘The mind is its own place, and in itself can make a heaven of hell, a hell of heaven’. This, along with the basic tenets of Buddhism, points to what has become the central tenet of psychological theories of stress: that appraisal is central to whether or not an event is deemed to be a stressor or not.

A key figure in this domain is Richard Lazarus, who with colleagues (e.g. Lazarus and Launier, 1978; Lazarus and Folkman, 1984) proposed what is called a cognitive transactional model of stress (Figure 11.1). According to Lazarus, stress is a result of an interaction between events in the external or internal event (stressor) environment, an individual’s appraisals of these events, and the internal or external resources a person has available to them. Motivational and cognitive variables are considered central. Lazarus’s initial model maintained that when individuals confront a new or changing environment, they engage in a two types of appraisal: primary and secondary.

### Primary appraisal processes

In primary appraisal, a person considers the quality and nature of the stimulus event. Lazarus distinguished three kinds of possible stressor: those that pose harm, those that threaten, and those that set a challenge. Harm is considered as damage that has already been done, that is, a loss or failure; threat is the expectation of future harm; and challenge results from demands that are appraised as opportunities for personal growth or opportunities that a person is confident about dealing with. Events not appraised as either harmful, threatening or challenging are considered to be benign and require no further action. Appraisals take the form of questions such as, ‘Is this event something I have to deal with?’ ‘Is it relevant to me?’ ‘If so, what is at stake?’ ‘Is it a positive, negative or neutral event? If potentially or actually negative, then is it posing me harm/threat or challenge?’ In parallel to these appraisals, emotions may arise that, as well as influencing coping, may elicit various physiological responses (see later).

### Secondary appraisal processes

At the same time as carrying out primary appraisals, Lazarus proposed that secondary **appraisals** occur whereby the individual assesses their resources and

**appraisals**
interpretations of situations, events or behaviour that a person makes.

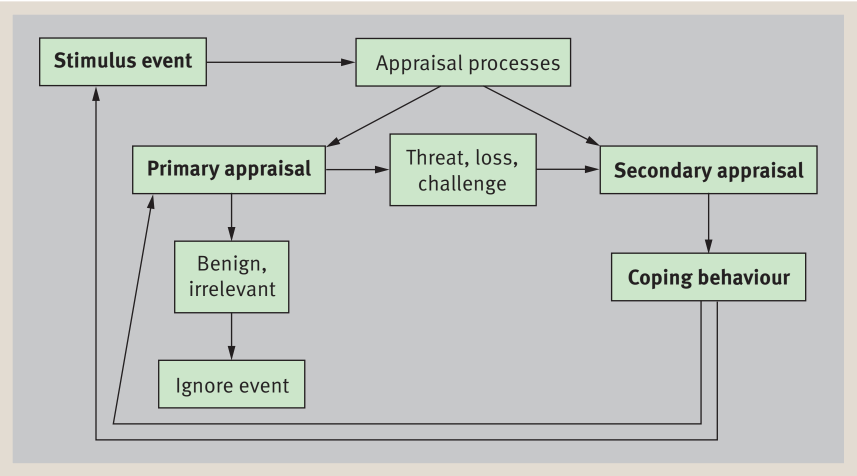


**Figure 11.1** Lazarus’s early transactional model of stress

*Source*: Adapted from Lovallo (1997: 77).

abilities to cope with the stressor (problem-focused or emotion-focused coping potential). The questions asked at this stage are of the type: ‘How am I going to deal with this?’ ‘What can I use or call upon to help me?’ Resources can be either internal (e.g. strength, determination) or external (e.g. social support, money).

Using forthcoming exams as an example, various appraisal judgments may be made, for example:

- ‘There is no way I can possibly deal with this. I simply know I will fail’ (threat + no resources = stress).
- ‘This will be really hard. I just am not as clever as the other students’ (threat + limited internal resources = stress).
- ‘Maybe I can manage this if I revise really hard’ (challenge + possible internal resources = less stress).
- ‘I could perhaps do it if I get some help from my friends’ (challenge + external resources = less stress).
- ‘This isn’t a problem. I know the material really well’ (benign).
- ‘I managed to pass the last time, I’ll be okay this time’ (benign).

Lazarus maintained that stress would be experienced when perceived harm or threat was high but perceived coping ability was low, whereas when perceived coping ability was appraised to be high (i.e. resources were considered to be available to deal with the threat), then stress was likely to be minimal. In other words, stress arose from a mismatch between perceived demands and resources, both of which could change over time. It is important that stress is viewed as a dynamic process.

## Developments in Lazarus’s framework

In the 1990s, Lazarus increasingly considered the appraisals associated with a number of different emotions within the stress process (Smith and Lazarus, 1993). In doing so they extended the number of types of appraisal that can be made and explored their links to specific emotions. Two, primary, appraisals appear linked to all emotions: the motivational relevance of a situation (that is, how important it is to the individual) and motivational congruence (that is, how consistent it is with the individual’s current goals). Negative emotions are associated with events that are relevant to the individual and are incongruent with their goals. The specific emotion experienced is then determined by a number of secondary appraisals.

Smith proposed that primary appraisal consists of two assessments:

- *motivational relevance*: the extent to which the event is relevant to the individual’s current goals or commitments (which may include abstract goals such as maintaining wellbeing, feelings of confidence and so on).
- *motivational congruence*, the extent to which the situation is perceived as congruent with current goals.

Thus, a student who receives a poor mark for an exam but believes the exam is neither important nor has implications for their overall grade may experience no or much less stress than one who believes the exam to be important and likely to impact on their degree grade and even career.

These primary appraisals label the event as important and worthy of attention. However, the specific emotion triggered by the event will be a consequence of what Lazarus and Smith called secondary appraisals. Anxiety, for example, is triggered by the individual being unsure whether they can cope with a potentially stressful situation, while depression will result from the belief that the negative situation definitely cannot be changed. Anger may be a consequence of believing that one has been unfairly treated. Less well articulated are the appraisals associated with positive emotions, but positive appraisals such as that of benefit, gain or challenge may precede emotions such as tranquillity, joy or hope (Folkman, 2008; Hulbert-Williams et al., 2013; Yih et al., 2020). The formal names and attributes of these secondary appraisals are:

- *Internal/external accountability (‘blame/credit’)*: concerned with attributing responsibility for the event – distinguishes between the emotions of anger (other-blame) and guilt (self-blame). Credit is less often studied but may associate with emotions such as pride.
- *Problem-focused coping potential*: considers the extent to which the situation is perceived as changeable by instrumental (practical, problem-focused) coping options. If the situation is perceived as changeable, hope or optimism will exist; if not then the emotions of sadness or helplessness will be elicited.
- *Emotion-focused coping potential*: concerned with perceiving an ability to cope emotionally with the situation. Perceptions of not being able to cope are associated with fear or anxiety.
- *Future expectancy concerning situational change*: refers to perceived possibilities of the situation being changeable, with perceptions of unchangeability associated with sadness.

**Photo 11.1** This is a good example of 'eustress', something positive and controlled, but nonetheless often considered stressful

*Source*: Val Morrison.

A third type of cognitive response to events, known as core relational theme, serve as a sort of gestalt or summary of beliefs about the nature of the event. They are immediate and occur in parallel to the appraisal and also contribute to specific emotional responses. Finally, this theory proposes that emotional impressions of events are stored in memory and will influence how we appraise the same event in any future encounters. The full associations between appraisals, core relational themes and emotions are outlined in Table 11.2.

In two examinations of this model (appraisals, core-relational themes and emotions) in a health-related context, one with patients experiencing a cancer diagnosis (Hulbert-Williams et al., 2013) and one with nursing staff experiencing a distressing work situation (Bennett and Lowe, 2008) we see that only some of the findings were consistent with Smith and Lazarus's theory. For example, for nurses some, but not all of the identified episodes were seen as personally relevant and incongruent with desired outcomes (thought to be necessary for the experience of stress to occur). In terms of appraisals and emotions only some theorised associations were confirmed, and some non-theorised associations emerged instead. For example, only among the nursing sample were anger scores significantly correlated with blaming others or holding others responsible for the situation, as the theory would propose, and among both samples anger was significantly correlated with a non-theorised core

**Table 11.2** Appraisals, core-relational themes and emotions

| Appraisal components | Core-relational theme | Emotion |
|---|---|---|
| Motivationally incongruent, motivationally relevant, other-accountability | Other-blame | Anger |
| Motivationally relevant, self-accountability | Self-blame | Guilt |
| Motivationally incongruent, motivationally relevant, low emotion-focused coping potential | Danger/threat | Fear/anxiety |
| Motivationally incongruent, motivationally relevant, low problem-focused coping potential, low future expectancy | Loss, helplessness | Sadness |
| Motivational relevance, motivational incongruence, problem-focused coping potential | Optimism | Hope/challenge |
| Motivational congruence | Success | Happiness |

*Source*: Adapted from Hulbert-Williams et al. (2013).

relational theme of situational unexpectedness. Anxiety among nurses, but not cancer patients, was associated, as theorised, with perceptions of threat. For nurses, effortful optimism (the belief the situation could be controlled with some degree of effort), low levels of belief in the ability to cope with the emotional consequence of the situation, confusion, and regret were associated with anxiety, whereas for cancer patients anxiety was significantly associated with self-blame and feelings of loss/helplessness, in fact these core relational themes emerged as the most commonly associated with a range of emotions.

What such findings suggest is that the theory may hold true in part, in some situations but not others, and that the relationships between appraisals and emotions are not straightforward. Developing one theory or model to ‘fit’ the complexity of the stress experience may be impossible.

## Criticism of Lazarus’s framework

Among the many advantages of the transactional approach and its cognitive appraisal theory is that it is compatible with both biological and social models, acknowledging as it does the role of the stimulus, of emotional and behavioural responses, of individual differences and of the external environment. There is a large body of supporting empirical evidence, and few studies of coping with stress or illness are conducted without acknowledging the central role of individual difference variables and appraisals, as will become quite evident in the subsequent chapter (see Chapter 12 ☛). However, no model or theory escapes without criticism, as this is one way in which academic understanding is advanced. Some criticisms include:

- Lazarus’s framework has an inherent circularity and little research has attempted to examine the nature of interaction between primary and secondary appraisals, i.e. between perceived demands and perceived coping resources leading to claims of the model being tautological (Hobfoll, 1989) – put simply, this means that whether an event is demanding or not depends on perceived coping capacity, and whether coping capacity is perceived as adequate or not is dependent on perceived demand!
- It is unclear whether both primary and secondary appraisals are necessary and indeed, do perceived demands need to outweigh perceived resources in order for stress to be experienced? Zohar and Dayan (1999) found positive mood outcomes in their sample to be affected mainly by coping potential (perceived resource) variables and not by primary appraisal variables. Additionally, stress arose and increased as the stakes or motivational relevance of an event increased, even in situations where coping potential was unlimited. Any slight uncertainty about coping potential modified the effect of ‘stakes’ (primary appraisal) on stress. For example, imagine a situation where you believe that a forthcoming mid-term examination is a ‘mock’ and does not count towards your final grade, but on turning up to the exam you are told that it is not a ‘mock’ but a ‘real’ exam. In spite of having revised the subject seriously and having no major concerns about your ability to answer the questions, this new situation is likely to be appraised differently because its value has changed (raised stakes), and the stress experience will therefore also change (increase), even though your resources (secondary appraisals of coping potential) have not.
- The nature of the role of appraisals/core relational themes has also been questioned. Do they ‘cause’ the emotions? Or are they a consequence of the emotions? Or are they part of the emotions? Or do all three propositions have some currency? As noted by Ferrer and Mendes (Ferrer and Mendes, 2016, p. 2), ‘both stress and emotion involve cognitive appraisals of predictability and controllability, social components, and elements of physical discomfort or pleasure, and both incorporate subjective experience and physical response’. It is therefore perhaps understandable that they are difficult to separate! Furthermore, the time-frame of the occurrence of appraisals (and other cognitive events) and their associated emotions makes it almost impossible to identify their temporal ordering. It is possible even that emotional responses to events that are repeats of, or similar to, previous experiences are classically conditioned and therefore independent of any cognitive precursor. In such cases it is not unreasonable to suggest that the appraisal follows a conditioned emotional response in order to make sense of the experience of any associated arousal.

In spite of these challenges, exploring changes in appraisals and emotions, and the relationships between them over time is crucial to our understanding of the illness experience and to the development and timing of effective interventions. In this regard, a longitudinal study of 160 cancer patients followed up at three and six months from a baseline (average 46 days from diagnosis) which tested Lazarus’s model found only one appraisal (motivational incongruence) and four core-relational themes (irrelevance, lack of concern, threat removal and success) changed significantly between baseline and three months, and between baseline and six month follow-up just one appraisal component (motivational incongruence) and six core-relational themes (relevance, irrelevance, lack of concern, threat, threat removal and success) changed. None of the typically examined emotions of anger or anxiety, for example, changed over time; only happiness between baseline and three months and shame/humiliation and relief changed between three and six months and in neither case did these correspond to changes in the theoretically associated appraisals, e.g. one would have expected a change in happiness to be associated with a change in motivational relevance, but it was not (Hulbert Williams et al., 2013). Identifying targets for interventions from such data are limited, however what this study did do, as noted earlier in this section, is show that appraisals are associated with many more emotions than typically addressed in the study of illness experience. Few studies examine feelings of relief, shame/humiliation or anger that, in these data, are associated with certain cognitions yet these cognitions and emotions often emerge in qualitative studies and are potentially powerful drivers of coping responses, as will be described in Chapter 12 ☛. This paper therefore serves to highlight the need to widen our scope when addressing the emotional experience of illnesses such as cancer and their associated treatments (see also Chapter 14 ☛).

**WHAT DO YOU THINK?**

Which do you think comes first – the thought (appraisal) or the emotion? Is it possible to order them? Think of a recent event that you were unhappy about – what thoughts were 'attached' to that unhappiness? Did your feelings about the event change over time and, if so, did your thoughts also change? What about an event that made you happy – WHY did it make you happy? Consider the thought processes. Does Lazarus's model make sense to you?

## What factors influence appraisal?

While the nature of stimulus events/potential stressors varies hugely – from, for example, receiving a final demand for an unpaid bill to being a victim of a natural disaster, from having a head cold to receiving a diagnosis of a life-threatening illness – certain features of events have been found to increase the likelihood of their being appraised as stressful. These are events that:

- are *imminent* (e.g. medical results due the next day; driving test that afternoon);
- occur at an *unexpected time* in life (e.g. being widowed in one's 40s compared with when in one's 70s; the death of a child);
- are *unpredictable* in nature (e.g. being made redundant; sudden bereavement);
- are *ambiguous* in terms of:
- personal role (e.g. starting a new job);
    - potential risk or harm involved (e.g. undergoing surgery, taking new medication);
    - events are undesirable (e.g. having to move house because of financial loss);
- the individual perceives *no control* over (behavioural or cognitive, e.g. noisy neighbours);
- events that elicit high amounts of *life change* (e.g. childbirth, relocation).

Further distinction has been drawn (e.g. Sapolsky, 1994: 5) between:

- acute physical stressors, which demand immediate physiological adaptation (e.g. being attacked);
- chronic physical stressors (e.g. being ill or surviving in a hostile environment);
- long-term physiological demands that we are not so good at dealing with, such as pain;
- psychosocial stressors, which involve our cognitions, emotions and behavioural responses as well as the physiological arousal that will be triggered.

Many psychologists would argue that all these are in fact psychosocial as they involve more than simply the event or stimulus. Chapter 12 ☛ will deal with the personal and inter-personal influences on appraisals and stress responses.

# Lay theories of stress

It is worth stopping to reflect on what has been made clear in the above review of the scientific study of stress – in spite of significant scientific enquiry, as a subjective construct 'stress' is hard to define. As in Chapter 9 ☛, where we described how lay models of illness are important to understanding processes of symptom perception, interpretation, and response, we need here to acknowledge the role played by the laypersons' view of the causes and consequences of stress – stress as a concept exists not only in scientific study but *also in our everyday language*. Several authors have studied these understandings in relation to work stress (e.g. Chartered Institute of Personnel Directors, 2011; Rystedt et al., 2004; Kinman and Jones, 2005; Jones et al., 2006) where multifaceted and variable models of stress were found. Interestingly, in one study, different models of the impact of stress and the responsibility for managing it were found depending on the rank/position of a person in a company, whereby lower-level workers considered stress impact to be more personal but requiring of joint efforts by themselves and the organisation if it were to be managed, whereas managerial workers considered that the responsibility for stress management lay at their own feet – in spite of agreeing that many causes of stress were organisational! (Kinman and Jones, 2005). Such lay beliefs are important, given that evidence of their longitudinal effects on worker stress, including mental strain (Rystedt et al., 2004), and their implications for stress management interventions (Chapter 13 ☛).

Others have studied understanding of stress in relation to specific illnesses, such as heart attack (e.g. Clark, 2003) or diabetes (Schoenberg et al., 2008). In Schoenberg's study of 80 adults of African American, Mexican American, White American or Great Lakes Indian origin, diagnosed with diabetes, stress was viewed as a) a cause or factor in diabetes onset b) a factor that directly affected or exacerbated the condition and its symptoms) a factor that undermined diabetes self-care practices such as dietary change or medication adherence, d) a precursor and a consequence of diabetes complications, and finally e) threaded throughout the other four themes were the existence of inadequate resources and stress inducing environments in the onset, course and consequences of participants' diabetes. Undifferentiated by ethnicity, the emerging lay models illustrated very clearly how participants contextualised the biomedical model of diabetes, sometimes contradicting biomedical explanations of their condition, with much wider biographical, psychosocial and relational explanations. In Clark's study of 14 Scottish heart attack survivors, there was a common view that stress was a more likely cause of their heart attack than even smoking or diet. Such beliefs could, of course, be self-serving; attributing poor health to an external source such as stress may absolve the individual of any feelings of personal responsibility for their condition and as such, 'clinicians who disregard stress in the lives of their patients may unwittingly undermine their own advice for warding off complications' (Schoenberg et al., 2008, p. 185).

Now, we turn our attention to potential sources of stress: 'potential' sources because, as described above, it is the situation – person interaction that determines whether a stress response follows a given stimulus.

# Types of stress

## Stress and resource loss

Hobfoll (1989) proposed a 'conservation of resources' model of stress whereby individuals are assumed to work to conserve or protect their valued resources (e.g. objects, roles, personal characteristics such as self-esteem, energy, time, money, skills) and that when there is actual or threatened loss of resources or a lack of gain after investing resources, stress will result. Resources are thought to be quantifiable and 'real' and Hobfoll states that the more resources are lost, the more difficult it is to replace them which results in greater stress, although even a gradual loss of resource can contribute to low mood and stress. Hobfoll et al. (2003), for example, found that among a sample of inner-city dwelling women, changes in their economic and social resources, both for the better and worse, were significantly associated with changes in depressive mood and anger. While the relationship between economic and social losses went both ways, the impact of negative changes was more profound than the gains associated with positive economic gains.

By focusing on loss of quantifiable entities rather than appraisals, this model avoids difficulties in distinguishing appraisals from responses. However, while the theory is clearly consistent with findings of higher levels of stress among individuals with poor economic or social circumstances (see Chapter 2 ☛), not everyone in such circumstances will experience markedly lower mood, anxiety or anger than those with more resources due to the individual differences we have described. Thus, while this model provides a clear role for the impact of external stressors; it adds to, rather than replaces, the appraisal models. Furthermore Marks et al. (2000) noted that the loss and resource constructs are not particularly well defined or easy to measure, and that many questions remain unanswered by this model. For example, how permanent must loss be for a person to experience stress? Is resource gain never stressful? (Some lottery winners would perhaps challenge this.)

As well as the impact of chronic stressors, Hobfoll (1991) found that rapid and extensive depletion of valued resources, such as that experienced following a natural disaster, was associated with traumatic stress responses thus allowing acute-onset stressors to have long-term consequences. It is to these issues we now turn.

## Acute stress

Studies of acute-onset stress generally distinguish between stimulus events that are rare but cataclysmic and more common acute stressors, such as exams.

### Cataclysmic events

Earthquakes, hurricanes and air disasters are rare events that allow a person little or no preparation time. Natural catastrophes, such as Hurricane Katrina in 2005, Californian forest fires in 2019–20 and technological disasters such as the nuclear meltdown in Japan in 2011, produce intense physical and psychosocial suffering for victims and for the 'worried well', i.e. those not actually in the disaster but affected by it in that it raises issues for them about their own personal safety and future. Environmental stress theory (Fisher et al., 1984; Baum, 1990) considers stress to be a combined psychological and physiological response to demands, and support for this can be found in the many psychological and physical symptoms reported in survivors of a natural calamity. These include:

- initial panic
- anxiety
- phobic fear
- vulnerability
- guilt (survivor guilt)
- isolation
- withdrawal (including some suicide attempts)
- anger and frustration
- interpersonal and marital problems
- disorientation
- lack of attachment
- loss of sense of security
- sleep disturbances
- eating disturbances.

The severity and duration of these effects seem to depend on the magnitude of the loss. However, as with more chronic stressors the individual's response to the acute event can either inflate or mitigate the long-term reaction. Perhaps the most dramatic outcome of experiencing a severe traumatic event is **post-traumatic stress disorder** (PTSD); characterised by flashback memories of the event, a tendency to ruminate about the event and its consequences and chronic hypervigilance (see Chapter 13 ☛). The most frequent cause of PTSD is road traffic accidents: about 22 per cent of those involved go on to develop some degree of PTSD (Lin et al., 2018). Rare but cataclysmic events that also receive massive media coverage have also been shown to raise the incidence of PTSD, as seen among participants in an early study of American's responses to the terrorist attacks of September 11th who reported increased exposure to TV media imagery in the days following the attacks (Silver et al., 2013). More recently, although not perhaps 'acute' in onset another example of cataclysmic stress with significant media coverage is the COVID-19 pandemic, where both direct experience of the virus and its treatment, caring for people with the virus (see 'Research focus'), simply living through the pandemic (Fofana et al., 2020) and being exposed to constant media exposure have contributed to significant trauma and anxiety (Garfin et al., 2020). Risk for this condition is associated with both the belief that one is going to die or feeling overwhelmed at the time of the event. By contract, reappraising the event as less threatening than initially thought may reduce the severity of PTSD (e.g., Marke and Bennett, 2013).

**post-traumatic stress disorder**

a disorder that forms a response to experiencing a traumatic event. The key elements are unwanted repetitive memories of the event, often in the form of flashbacks, attempts at avoidance of such memories, and a generally raised level of arousal.

**Photo 11.2** Floods in UK have cost many families much more than money – their home, possessions and memories are often lost in mud.

*Source*: Ian Forsyth/Getty Images News/Getty Images.

It is clear that acute-onset stressors can have chronic effects on a person's psychological wellbeing and thus interventions to minimise distress should be targeted appropriately. For example, in the case of hurricane survivors, interventions should target both the lost resources (e.g. restoration of housing, water, clothing) and the emotions and cognitions (e.g. self-efficacy) of the victims. Stress management and coping-based interventions are discussed fully in Chapter 13 ☛.

## Exam stress

Cohen et al. (1986) was one of the first people to show experimentally that high levels of perceived stress can impair people's memory and attention during cognitive activities. For example, many students report the experience of having the answer to questions on the tip of their tongue, and even memories of revising it the night before, but being unable to remember it once in the exam setting. Others will misread and misinterpret clearly written questions. It has been found that there is an optimum level of arousal necessary to maintain attention and memory, but that too little arousal, or too much, can be detrimental to one's performance. This is known as the Yerkes–Dodson law, first described in 1908 (see Figure 11.2). An exam in a subject where the result is desired and valued (motivationally relevant and congruent) will generally elicit more arousal than an exam that is not. The key to good performance lies in not becoming over-aroused so that all the learning goes to waste and the mind empties in the exam room!

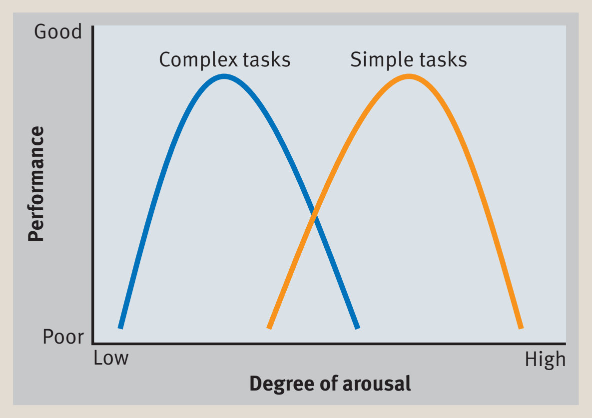


**Figure 11.2** The Yerkes–Dodson law

*Source*: Rice (1992: 5).

Exam stress has been associated with increased smoking, increased alcohol consumption, poor eating, increased caffeine intake, and less physical activity, and was attributed to a breakdown in self-control, particularly among those with poor study skills, as evidenced in a study of Australian students (Oaten and Cheng, 2006). These links between stress and behaviour form an indirect route through which stress can be considered to influence illness status. One example of the relatively short-term influence of acute stress on health is an increased susceptibility to immune-mediated diseases such as virus infections. Exams and the build-up to them (which is often accompanied by anxiety and changed behaviours such as increased consumption of cigarettes and alcohol) are sufficiently stressful to increase susceptibility to illness, through dysregulation of the immune system (Brosschot et al., 2005; Vedhara and Irwin, 2005; see also the later section, 'Stress as a physiological response'). However, exam stress may also have a longer-term impact on health if it forms part of a wider pattern of acute stressors. While single acute episodes of high blood pressure (commonly assessed in research studies as indices of **stress reactivity**) are likely to have minimal effects of health, repeated episodes over time, particularly for people who may be inherently more stress-reactive than others, can lead to more chronic blood pressure elevation and contribute to the development of long-term conditions underpinning heart disease (see later section, 'Stress and illness').

**stress reactivity**

the physiological arousal, such as increased heart rate or blood pressure, experienced during a potentially stressful encounter.

## RESEARCH FOCUS

### The experience of NHS frontline staff during the first wave of COVID-19

Bennett, P., Noble, S.., Johnston, S., Jones, D. and Hunter, R. (2020). COVID-19 confessions: a qualitative exploration of healthcare workers experiences of working with COVID-19. BMJ Open, 10: e043949.

This qualitative study was the first to report UK health professionals' experiences of caring for covid-19 patients. Unlike most qualitative studies which rely on a semi-structured interview and responses to interviewer questions, participants were given access to a confidential online recording facility where they could leave their anonymous messages with no prompts or barriers to what they said. The aim was to facilitate honest accounts of their most pertinent experiences, thoughts, and feelings with no restraints that may occur in the presence of an interviewer.

### Method

Participants were healthcare workers of all types, alerted to the study by tweets from two doctors (intensive care and palliative care consultant) with a large twitter following. Their tweets described the study and gave a web address through which participants could access the recording process. Once at the website, potential participants completed a digital consent form, a brief demographic questionnaire, and recorded their story either verbally or in written form. All audio recordings were deleted once transcribed. A total of 54 people (including 27 doctors, 13 nurses, two physiotherapists, and 10 other) completed the recordings.

### Findings

Transcripts of audio and written data were analysed using the inductive thematic analysis of Braun and Clarke. In this, extracts and phrases were used to identify potential themes, with relevant data (‘quotes’) gathered within identified themes. Five broad themes emerged: (i) Trauma and PTSD, (ii) Collateral damage, (iii) Hierarchy of power and inequality, and (iv), Staff sacrifice and dedication.

### Trauma and PTSD

Workers reported that they found their work both immensely rewarding and highly traumatising, with the costs often outweighing the positives. Many talked about feeling ‘broken’ and traumatised by the process of care: ‘I felt so inadequate and tried my very best to make sure these poor patients had ... medication. Staff were in tears and I watched a group of cardiology nurses cry as they tried to cope with patients with severe Covid’. ‘They were the most sick people I’ve ever seen and there are so many people dying ..... The thought of people saying ‘bye to relatives via Skype just absolutely broke me every single day, and I cried and cried and cried about it when I got home.’ Patients were also reported to be experiencing trauma: ‘They don’t sleep. They have nightmares .... one man doesn’t sleep because he’s worried that if he goes to sleep, he’ll never wake up again.’

### Collateral damage

A number of types of ‘collateral damage’ were also reported. These ranged from the fear of being infected by the virus (‘We wanted to make changes but were not heard. We’ve had staff die on our wards. I was reprimanded for wearing gloves and a pathetic ‘pinnie [apron] on the ward before one member of staff member died, because it wasn’t approved policy yet and we would worry patients’) to concerns that patients with significant non-COVID-19 related needs, including significant mental disability and health issues, were being marginalised: ‘Only two patients on ITU have COVID. The rest are people at death’s door from suicide attempts. All have a history of mental illness, all known to mental health services. All having had a sequential deterioration over the lockdown period with reduction in mental health support services, community projects, peer support, drop ins etc.’

### Hierarchy and inequality

Many participants reported anger as a consequence of a disconnect between senior management, colleagues, and front-line staff: ‘If anything, please can we take from this, that a white middle class manager, working from HOME has absolutely NO PLACE in assigning risk to any front-line staff seeing febrile and sick unscreened patients daily. That has happened to BAME employees in my organisation.’ ‘Many participants felt abandoned by their organisation and poorly supported trainees felt like being left as sacrificial fodder.’ ‘Frequently frustrations and conflict emerged between staff groups, notably where GPs won’t see anyone but us nurse practitioners are expected to.’

### Staff sacrifice and dedication

Despite the trauma of care and disjunction between professionals and management, there were many stories were of staff going ‘above and beyond’ the boundaries of normal care: ‘My clinical colleagues have been unbelievable. Adaptable, honest, efficient, true to patient need. Facing fear head on. Maintaining polite lines of conversation despite internally screaming at management types that it’s too little, too late.’ ‘We have bent over backwards to flex towards patient need .... Many of us now have COVID but there hasn’t been a shift unfilled. We want to step up to demand, for our patients and organisation. Yet ... HR are demoralising us.’ Ironically, perhaps, staff at most personal risk were involved in the most intimate contact with patients: ‘We were told of course that it should be the most senior person intubating, but also that they were the people probably at highest risk! And so I can see the look almost a fear in the eyes of some of my consulting colleagues.’

### Discussion

Caring for COVID-19 patients during the first wave of the pandemic was clearly stressful (to put it mildly) with staff making ‘Herculean’ efforts to manage their workload despite its traumatic nature, exhaustion, and personal risk of infection. Nonetheless, the stories also reported significant dislocations between various health professions and senior management and warned that this level of effort cannot be assumed long-term without significant burnout and even people leaving the NHS. The NHS needs to mitigate such stresses as much as possible in future pandemic waves.

# Chronic stress

## Occupational stress

Most working individuals will experience workplace stress at some point, and while for many it is short-lived or manageable, for others it is chronic and damaging, being accompanied, for example, by changes in eating or sleep patterns, fatigue or relationship strain. These are often discussed within the context of 'burnout' (e.g. Wang et al., 2007, 2008) (see 'In the spotlight').

What is it about some jobs which makes them so stressful? Interestingly, and in contrast to early intuitive models which considered occupational stress to be the realm of white-collar workers making high-level decisions, more recent theories place stress throughout the entire workforce. Indeed, underload, as well as overload, has been found stressful, with frustration and boredom proving as stressful for some employees as overload. This highlights a point central to the study of stress: each individual will construct their own definition of what is stressful 'for them' – this relates to person–environment fit theories (cf. Rauthman et al., 2021), or the earlier 'goodness-of-fit' approach described by Lazarus (1991b). Such approaches suggest that stress arises because of a mismatch between environmental variables (demands) and person variables (resources) and as we have said already, these vary within and between individuals. 'Fit' itself is dynamic rather than static, in that demands and resources can change over time. Early work focused more on environmental features of the workplace than on individual difference variables, for example the job demand–control (JDC) model of occupational stress, or job strain, put forward by Karasek and colleagues (e.g. Karasek et al., 1981; Karasek and Theorell, 1990). The job features identified as leading to stress included:

- demand
- controllability
- predictability
- ambiguity.

Each of these broad features can be assessed with specific questions, as illustrated in Table 11.3.

Karasek's well-tested model proposed that a combination of demand and control would determine whether or not the employee experienced stress (high demand and low control contributing to higher stress–strain than would situations of high demand and high control). However, while it was initially thought that perceived or actual control acted as a moderator of demand (i.e. that control 'buffered' the negative effects of demands), only minimal evidence that control moderated the negative impact of high work demands upon wellbeing, or burn-out (see 'In the spotlight') have been reported (Rafferty et al., 2001). It appears that demand and control have independent and direct effects on stress outcomes. This then impacts on health. Kivimäki and Kawachi's (2015) meta-analysis, for example, found a 10–40 per cent increased risk for CHD and stroke among individuals with high job strain.

As well as better specifying the control component, it was proposed that social support, or lack of it, needed to be added to the model. Pisanti (2012), for example, found that job demands and (lack of) social support were key predictors of distress and burnout in a sample of Italian

**Table 11.3** Examples of items to assess work-related stress

| | Never | Rarely | Sometimes | Often | Most times |
|---|---|---|---|---|---|
| Demand | | | | | |
| ● My workload is never-ending | | | | | |
| ● Job deadlines are constant | | | | | |
| ● My job is very exciting | | | | | |
| Control | | | | | |
| ● I have autonomy in carrying out my duties | | | | | |
| ● There are too many bosses | | | | | |
| Predictability | | | | | |
| ● My job consists of responding to emergencies | | | | | |
| ● I am never sure what will be expected of me | | | | | |
| Ambiguity | | | | | |
| ● My job is not very well defined | | | | | |
| ● I am not sure about what is expected of me | | | | | |

*Source*: Adapted from Rice (1992: 188–92).

nurses. Others have suggested adding a more general ‘resources’ component (Demerouti et al., 2001) whereby resources could include social support, or aspects of personal control, etc. A further alternative model to that of Karasek’s is the Effort/Reward Imbalance model (Siegrist et al., 2004) which highlights what the individual ‘puts in’ to their work and notes how a lack of recognition or return for effort can be stressful and result in significant health challenges including high cholesterol and blood pressure, compromised immune function and inflammation and heart disease (see, Siegrist and Li, 2017). For example, an over-commitment to work has been associated with increased blood pressure (Steptoe et al., 2004a); job strain and an effort/reward imbalance significantly predicted risk of CVD mortality over 25 years of the Whitehall II Study (Kivimäki et al., 2002) while Dragano et al.’s (2017) study of over 90,000 workers also revealed modest but significant associations between effort-reward imbalance and the development of heart disease. Bosch et al. (2009) found high effort–reward imbalance to be associated with impaired immune function, to the extent they considered them to ‘contribute to immunological ageing’.

## IN THE SPOTLIGHT

### Occupational burnout

Chronic ongoing stressors such as permanently excessive workload demands are thought to create stress in employees, as are sudden, unexpected requests or interruptions, being pushed to make a decision, not having the latitude to take decisions, or being unclear as to what is expected of one. That stress is subjective is seen in the findings of an idiographic study of the meaning of stress to five health professionals (neurological consultant – NC, ophthalmology assistant – OA, paediatrician – P, psychiatrist – PS and theatre nurse – TN) where aspects listed as the most stressful included work environment factors such as monotonous tasks (NC), maintaining cleanliness (TN), time pressures (NC, TN), full waiting room (P), overload (NC), poor pay or conditions (OA) as well as external factors such as family pressure (PS, P) (Kirkcaldy et al., 2000).

When stressors are ongoing, burnout may occur. Maslach (1997) defined burn-out as a three-part syndrome of gradually developing emotional exhaustion, depersonalisation and reduced personal accomplishment that occurs among individuals who work with people in some capacity, and which can be associated with both physical and mental ill health. Burn-out is similar to the final stage of Selye’s general adaptation syndrome (see later): i.e. exhaustion, both mental and physical. Experienced as feelings of being overwhelmed, drained and unable to meet constant demands, many studies have identified a high incidence of burnout among healthcare professionals: hospital consultants (e.g. Taylor et al., 2005), nurses (e.g. Jones and Johnston, 2000; Allan et al., 2009), and those working with cancer patients (e.g. Barnard et al., 2006; Trufelli et al., 2008). The implications of staff stress and burnout for those clients or patients in receipt of their care has also been raised by clinical psychologists who report unhappiness with their work environments and changing systems (Webb, 2013).

Burnout builds up gradually and insiduously but can have a major impact on both emotional and physical wellbeing – with prolonged experience of stress reducing immune function, disturbing sleep, changing behavioural habits (as described earlier), and potentially reducing productivity and leading to sickness absence. A review of 57 studies of workplace stress and immune function conducted by Eddy and colleagues (Eddy et al., 2016) found that over commitment and lack of rewards for effort, were particularly associated. Burnout is exacerbated by feelings of hopelessness or lack of control, and by a lack of behavioural or emotional escape through social interactions (also curtailed for example during the recent COVID-19 pandemic).

Burnout has in fact become a concern during 2020–21 within the NHS during the COVID-19 pandemic, with exhaustion and intense emotion seen in the often harrowing media interviews with both junior and senior healthcare staff. The stresses of caring for patients with COVID-19 in under-resourced healthcare systems has led to high levels of burnout (Mollica, Fernando and Augusterfer, 2021) and many health professionals deciding to leave the healthcare system as a consequence (Bennett et al., 2020).

As well as within the healthcare sector (see 'In the spotlight') many studies have addressed stress within educational sectors. For example, teachers report stress arising from a range of factors, including poor classroom conditions and lack of materials or equipment, frequent reorganisation in school policy or practice both internally and externally imposed, challenging pupil conduct, and excessive workload/job demands carried over to home (e.g. Griva and Joekes, 2003; Skaalvik and Skaalvik, 2009). Undergraduate students are of course not exempt from stress; in fact, undergraduates have a higher prevalence of mental health problems than age-matched non-students. These problems disrupt performance (Royal College of Psychiatrists, 2003) and are rising significantly over the past years (e.g. Beiter et al., 2015). The impact of austerity measures on staff recruitment or facilities is felt at many levels, including in Higher Education where job insecurity, poor work relationships, lack of control, lack of resources and poor communication are the most frequently cited sources of staff stress (Tytherleigh et al., 2005) with a significant increase seen in referrals to mental health or counselling services between 2009 and 2016 (Morrish, 2019). Given the current climate of austerity across Europe, more of us may be experiencing mental, emotional and physical ill health, given evidence of their higher levels among those experiencing financial pressures (e.g. Jessop et al., 2005, and see Chapter 2 ☛).

It is worth noting however that not all studies have found an association between workload itself and levels of burnout, (e.g. see McVicar, 2003 for a review). Several reasons might exist for differences in study findings:

- sample or setting differences (e.g. registered general nurses vs. palliative or hospice nurses; staff level within implicit hierarchies);
- varying individual characteristics and responses made to the demands;
- whether demands, resources or both were assessed.

Also worthy of mention is that certain occupations, such as healthcare professions, or occupying certain positions within an occupation (i.e. senior management) may also have strong internal sanctions (perceived or actual) against acknowledging, exhibiting or reporting symptoms of stress. This may influence what has been reported in our studies, and will likely create bias in reported characteristics of those seeking support.

Different job types do also contain different objective demands: shift workers or factory workers, for example have particular challenges to face (unsocial hours, repetition), as do those working in a high-risk environment (e.g. firefighters, prison officers) or those having to deal with the public (see Park et al., 2014). Secondly, individual characteristics and coping responses show variable associations with job stress: for example, teachers with a stronger sense of competence report less stress and appear to cope more effectively (e.g. Schwarzer and Hallum, 2008) (see Chapter 12 ☛ for further discussion of coping). Of note in this context are findings that workload-specific stress factors were more strongly associated with mood disturbance than nurses' coping responses (Healy and McKay, 2000; Bennett et al., 2001). Bennett concluded that constraints over the strategies nurses could use to manage their work demands (the classic Karasek high demand–low control dimension) may have mitigated the impact of any personal coping strategies they could utilise at work, and contrasted this to their findings that key predictors of doctor stress were their own personal coping responses.

Of particular note is the contention that job demands are more likely to predict emotional exhaustion, whereas job resources, or lack of them (e.g. low perceived control), would be associated with disengagement and lack of accomplishment. In a meta-analysis of 71 independent samples with over 48,000 participants where job control was considered as a resource within the Conservation of Resources model (see earlier), this hypothesis was confirmed (Park et al., 2014).

It has been suggested that men would benefit more than women from work-based interventions to reduce stress and improve wellbeing, following reasonably consistent findings that men are less likely to seek out support for stress elsewhere and that a sense of identity and self-worth arising from positive work experience is more salient to men's experience (World Economic Forum, 2008).

## WHAT DO YOU THINK?

Are you feeling stressed? If not, then that is good news! If you are though, what do you think is currently contributing to this feeling? As a student, are there aspects of your workload in your list? If so, what are the features of your workload that are making it stressful? Is it that the demands (real or perceived) are too great and your resources (real or perceived) too low? Is it about ambiguity of others' expectations of you or a perceived or actual lack of control over the situation? Is it that you have other things you would rather be doing, other goals and desires distracting or competing for your attention? Once you have a better sense of what features your stress triggers have, it becomes easier to work out the appropriate solution (see Chapter 13 ☛).

The commonly employed models of occupational stress described here have therefore succeeded in integrating what the individual brings to the workplace (personal characteristics, cognitions, effort), their support resources and the environmental features. Depending on which contributing factor one addresses, interventions have potentially different targets to attempt stress reduction and management (see Chapter 13 ☛). Aspects of the individual such as their resources, their coping strategies, their health-damaging behaviours such as increased smoking or alcohol consumption, or their use of social support are potentially more amenable to intervention that attempts to challenge or resolve issues of job control, decision latitude, overload, underload or ambiguity of role with one's employer! Training of management or supervisory staff can, however, help them to better communicate to their workforce, to delegate responsibility and to bolster worker confidence (see Park et al.'s meta-analysis, 2014). In addition, reported conflict with or harassment by colleagues has been associated with significant levels of staff absenteeism, to the extent that in 2002 the Royal College of Nursing (RCN, 2002) acknowledged a need to improve inter- and intra- professional communication and management style. The consequences of stress-related sickness, presenteeism (attending work when sick or disengaged for example due to a trauma) and absenteeism, carry huge costs for employers in terms of loss of productivity, staffing shortages and accidents in the workplace (Morrish, 2018). A study of 1,440 German pharmaceutical company employees, comparing the main job-stress models described here in fact found that a model of stress built around perceived 'organisational injustice' was a more significant cause of absenteeism than models based on 'over-commitment', 'effort-reward imbalance' or 'job demand-control'(Schmidt et al., 2019).

Overall, findings point to a need for workplace-based interventions which target both the work environment and individual's wellbeing at an early point for the benefit of physical and emotional wellbeing and also productivity – outcomes of importance to both employee and employer (e.g. Brabantia Work Health Program, Maes and van der Doef, 2004).

So far we have established that stress responses arise from events and from appraisals of these events, but we have not yet described what happens next! Lazarus's transactional model of stress posits that appraisals and their attached emotions lead to cognitive and behavioural coping efforts, and in Chapter 12 ☛ coping theory and the role of coping in moderating stress outcomes is discussed fully. However, in addition to these psychological stress responses, stress can also trigger biological and physiological responses, and it is to these that we now turn our attention.

## Stress as a physiological response

Thinking of stress as a response takes us into the domain of seeking biological or physiological explanations of how stress affects the body and potentially illness; the assumption here is that stressors place demands on the person that are manifested in some response; in physics, this response would be termed 'strain'. Proponents of the 'response' model of stress describe how individuals react to danger or potentially harmful situations or even pleasant demands with a coordinated physiological and behavioural response (e.g. Cassel, 1974, cited in Leventhal and Tomarken, 1987). Initially, an event has to be appraised, and this involves the **central nervous system** (CNS). The sensory information and the appraisal of the event combine to initiate autonomic and endocrine (hormone) responses. The autonomic nervous system is part of the peripheral nervous system and contains both the sympathetic and the parasympathetic NS (see below). These responses in turn feed back to the cortex and limbic system, which in turn links with the

**central nervous system**
that part of the nervous system consisting of the brain and spinal cord.

hypothalamus and brainstem. It has been found that, for example, appraising an event as unpredictable in nature affects various aspects of physiological activation, for example, in terms of lymphocyte activation (Zakowski, 1995) or levels of cortisol sampled in commuters (Evans et al., 2002).

These processes are summarised below, although Chapter 8 ☛ provides greater physiological definition and detail.

## Early work on the physical stress response

An early researcher, Walter Cannon (1932), outlined the role of catecholamines (adrenaline and noradrenaline), which, when released from the adrenal glands of the sympathetic nervous system as hormones, heighten arousal in order to facilitate the 'fight or flight' response. When faced with imminent danger or a high level of threat (such as when being charged at by an angry dog), the options are to face the challenge or escape it. This natural response of physical arousal – dry mouth, increased heart rate, rapid breathing – signifies the release of adrenaline, a hormone that enlarges the autonomic responses (e.g. breathing deeply, a rapid heart rate) and facilitates the release of stored fuels for energy, which enables either running away or fighting the threat. This 'fight or flight syndrome', Cannon reasoned, was *adaptive* because it enabled quick responses to threat but also *harmful* because it disrupted emotional and physiological functioning. If prolonged, such responses were thought to contribute to many medical problems, (based on early animal studies whereby dogs and monkeys were exposed to prolonged periods of stress causing excessive hydrochloric acid to build up in the stomach, thus contributing to ulcer formation). In other words, in situations of chronic or ongoing stress, this fight–flight response would not be adaptive.

Subsequent to Cannon, another physiologist, Hans Selye (1956), discovered (quite accidentally while conducting animal research into the sex hormones) that a triad of responses commonly followed the unpleasant injecting procedures used – the adrenal glands enlarged, the thymus gland shrank and ulcers developed in the digestive tract. He followed up his early findings with over forty years of research using different aversive stimuli (injections, heat, cold, exercise), and came to the conclusion that there were universal and non-specific responses to stress: i.e. the same physiological responses followed a range of stimuli, whether pleasant or unpleasant, and that the 'fight–flight' response was only the first stage of response to stress (e.g. Selye, 1974). Selye's model of stress is known as the **general adaptation syndrome**. The response to stress was seen to be an innate drive of living organisms to maintain internal balance, i.e. homeostasis, and he proposed that it did so in a three-stage process:

1. *Alarm reaction*: awareness of a stressor can cause a downturn in bodily defences, as blood pressure and heart rate may initially fall before rising to higher than normal levels. Once raised, Selye noted, this arousal could not be maintained for long periods. He attributed his stress response to activation of the anterior–pituitary–adrenal cortex system, although exact physiological processes only became clear some years later (Selye, 1991; Pinel, 2003; and see later section).
2. *Stage of resistance*: the next stage is where the body mobilises its bodily defences to try to adapt to a stressor that has not subsided in spite of resistance efforts made during the alarm stage. While physiological arousal is less than during the alarm stage it is still higher than normal. Selye noted that this stage could not last indefinitely without the organism becoming vulnerable to illness.
3. *Stage of exhaustion:* if the resistance stage lasts too long, a depletion of bodily resources and energy would result in exhaustion (see 'In the spotlight'). At this stage, the ability to resist the stress declines and at this point, Selye proposed, the increased likelihood of 'diseases of adaptation' such as cardiovascular disease, arthritis and asthma.

general adaptation syndrome

a sequence of physiological responses to prolonged stress, from the alarm stage through the resistance stage to exhaustion.

## Later work on physical stress responses

### Tend and befriend responses

While Cannon's and Selye's work stimulated a huge amount of research into the physiology of stress, much of it has not confirmed the presence of a consistent 'non-specific response'. Different physiological responses have been found to be associated with different kinds of stressor, for example mental stress compared to physical stress, in addition when faced with something potentially stressful, our options are greater than an initial 'fight or flight' response. Taylor (2002, 2012) describes a 'tend and befriend' response whereby stress can elicit prosocial and affiliative behaviours that involve looking after others and seeking support, which may be beneficial in dealing with more long-term stressors. Experimental work with animals and with humans have found that these responses, seen predominantly in females, are associated with the release of the hormone oxytocin, which appears to reduce other physiological reactions to stress and associated psychological distress (Taylor, 2012 and see also the discussion of the benefits of social support in Chapter 12 ☛).

### The SAM (sympathetic–adrenomedullary system) and the HPA (hypothalamic–pituitary–adrenocortical) system

There is no doubt, however, that both adverse events and positive events produce physiological changes. A large body of evidence shows that typical stress responses (e.g. rapid and deeper breathing, increased heart rate, sweating or shaking) result not just from activation of the anterior–pituitary–adrenal cortex system (as Selye thought) but also from increased activity of the sympathetic branch of the autonomic nervous system (ANS). The ANS can be divided into two connected systems – the sympathetic nervous system (SNS) and the parasympathetic nervous system (PNS) – which 'exist in a state of dynamic but antagonistic tension' (Rice, 1992: 126). The SNS is involved in arousal and expenditure of energy (such as during a 'fight–flight' response), whereas the PNS is involved in reducing arousal and in restoring and conserving the body's energy stores (such as during rest) (see Chapter 8 ☛).

Both neural systems control the actions of many internal organs, such as the heart and skeletal muscles, with their activity initially mediated by the neurotransmitter acetylcholine. Acetylcholine links the neurons of the spinal synapse to the brainstem, where the nerves then act on their target organs. Mediation in the sympathetic branch is provided by noradrenaline (adrenergic fibres) and, to a lesser degree, adrenaline; whereas in the parasympathetic branch, acetylcholine (cholinergic fibres) makes this final link.

Activation of the sympathetic–adrenomedullary system (SAM) results in release of the catecholamines adrenaline and noradrenaline (epinephrine and norepinephrine being the US terms) from the adrenal medulla (the adrenal medulla and the adrenal cortex comprise the adrenal glands). This activation which is triggered from the hypothalamus, which sends nerves signals down to the adrenal medulla via the spinal cord, enables a person to make an immediate response to a stressor, such as 'flight or fight' enabled by adrenalin being released into the bloodstream.

However, the stress response following sympathetic arousal is short-lived and therefore the endocrine (hormonal) system, in fact neuroendocrine (combining the nervous and the endocrine systems, i.e. electrical/chemical and hormonal), responses follow. This second system, the hypothalamic–pituitary–adrenocortical (HPA) system (see Figure 11.3), enables our bodily organs to alter their usual function to facilitate a longer lasting adaptive response to both internal and external stresses. This system also originates in the hypothalamus, which releases its own hormone, corticotrophin-releasing factor (CRF), which controls the anterior pituitary gland at the base of the brain in its secreting of adrenocorticotrophic hormone (ACTH). ACTH then travels to the adrenal cortex, which then secretes glucocorticoids, particularly the hormone cortisol, which is stimulated from the adrenal cortex.

While Cannon's early model described the role of adrenaline, Selye was more interested in such adrenocortical responses, and in fact it is the HPA system that has received most research attention. We now know that circulating glucocorticoids provide energy for the 'alarm phase' as the release of glucocorticoids into the bloodstream regulates the levels of glucose in the blood from which energy can be drawn. Almost every cell in the human body contains glucocorticoid receptors, and

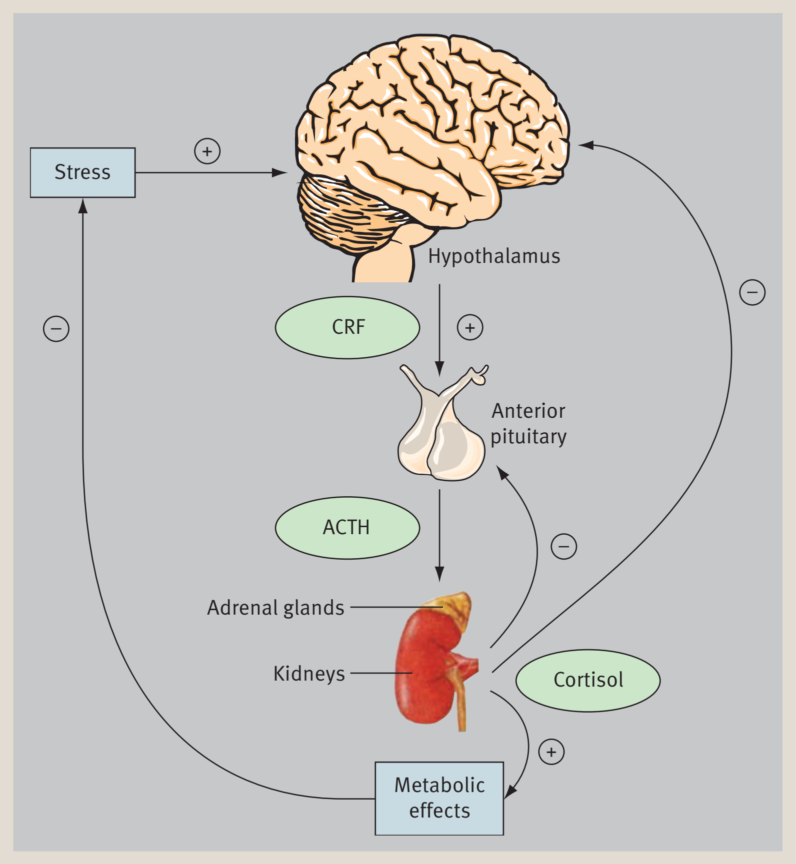


**Figure 11.3** Schematic diagram of the hypothalamus-pituitary-adrenal (HPA) axis. Stimulatory and inhibitory paths are indicated by the arrows and + or – signs respectively. CRF represents corticotropin releasing factor and ACTH represents adrenocorticotropic hormone.

*Source*: Adapted from Lenbury and Pornsawad (2005).

hormones such as cortisol affect every major organ system in the body. For example, cortisol inhibits glucose and fat uptake by tissue cells so that more can be drawn on for immediate energy; it increases blood flow, it suppresses immune function by inhibiting the action of phagocytes and lymphocytes, and it inhibits inflammation of any damaged tissue that is sustained during the fight or 'flight' (e.g. Kemeny, 2003). Blood cortisol levels are at their peak 20–40 minutes after a stressor and thus their levels have been used as stress indices in many studies.

The duration of some of the physiological responses to stress, such as the release of cortisol, influences whether the responses are beneficial to the organism or not. Initially released to support the body's initial stress response, levels of cortisol would typically return to normal levels within 40-60 minutes; however where it's release is prolonged, as is the case during prolonged internal or external stressors, this can actually have negative effects. The suppression of the immune system caused by increased blood-circulating cortisol (serum or s-cortisol) can make a person vulnerable to infection. Disruptions in the HPA axis, for example an overactive pituitary gland, can lead to abnormally high cortisol level, as seen in people with Cushing's disease (typified by bloating, atypical facial hair). Cortisol levels are also known to be elevated in those with sleep deprivation. Steptoe et al. (2004b), for example, found that people with low self-esteem had larger cortisol responses to wakening in the morning as they considered the day ahead, as well as sleep problems. By contrast, the same research group (Steptoe et al., 2005) found that the more positive affective experiences individuals had during the day, the lower their production of cortisol. Prolonged release of adrenaline and noradrenaline can also have negative results, including suppressed cellular immune function, increases in heart rate and blood pressure, heartbeat irregularities (arrhythmia) and, potentially, hypertension and heart disease (e.g. Pan et al., 2015). Potentially, therefore, by teaching people to manage stress and engage in positive psychology practices such as meditation, physiological responses to stress could be optimised (e.g. Manigault et al., 2019).

HPA activation also elevates the production of growth hormones and prolactin, beta endorphins and encephalin, which are also found in the brain in response to stress. Beta endorphins have a useful analgesic (pain-killing) function and, as such, may explain why people can endure high levels of pain until they succeed in escaping stressful situations or completing demanding tasks: for example, soldiers with extreme injuries have been known to crawl long distances to receive help, and athletes can complete races in spite of damaged muscles (see Chapter 16 ☛ for a discussion of psychobiological theories of pain).

## Cortisol and ageing

Interestingly, also, there is some suggestion of an association between cortisol and processes central to ageing. Animal research has shown that long-term exposure to such glucocorticoids damaged neurons in the hippocampal formation (e.g. Coburn-Litvak et al., 2003), an area of the brain crucial to learning and memory (e.g. Magri et al., 2006). Magri and colleagues interpreted the increased cortisol levels found in older individuals as evidence of a reduced ability to adapt to stress, and possibly related to cognitive declines associated with dementia. This has now been confirmed by a range of studies which have shown high levels of cortisol to be associated with relatively poor cognitive functioning, including measures of episodic memory, executive functioning, language, spatial memory, processing speed, and social cognition and increasing risk for dementia (see Ouanes and Popp, 2019).

Overall, SAM and HPA systems, one operating via adrenaline for acute responses such as fight or flight, and one via cortisol for more sustained responses work within the autonomic nervous system and the endocrine system to prepare our bodies to meet the demands of our environment. Our autonomic nervous system may work 'behind the scenes', but its functions are essential to basic human responses.

## Neurological processes

However, some differences in stress responses may be attributable to neurological processes occurring even before the activation of the SAM and PAC. According to Gray (1983) stress and distress is associated with overactivation of a brain system involving the septo-hippocampal system (linking the septum, amygdala, hippocampus and fornix) and the Papez circuit (otherwise known as the circuit of emotion: linking the mammillary bodies, thalamus, cingulate gyrus and hippocampus, pre-frontal cortex, amygdala and septum). Gray (1983) called this the behavioural inhibition system (BIS), because activation of these brain circuits is thought to interrupt ongoing behaviour, and redirect attention to signs of threat or danger. According to Gray, the BIS receives information about the environment from the sensory cortex. It then checks this against predictions it makes about future threat changes. When a mismatch occurs, the system is activated and the individual experiences distress or anxiety. It is proposed that in these states the criteria may be 'set' too low, resulting in the individual constantly responding to perceived mismatches and the system being chronically activated.

Central to the development and maintenance of stress/anxiety are the brain's amygdala and hypothalamus. The amygdala modulates our experience of anxiety, aggression, fear conditioning and emotional memory. It has links to the hypothalamus which regulates the ANS response to these experiences: the fight-flight response. Activity within the amygdala is modulated through the neurotransmitters serotonin and GABA. Low levels of serotonin within the amygdala are associated with high levels of fear. Low levels of serotonin lead to low levels of GABA (Lee et al., 2013), and low levels of GABA within the amygdala result in a low threshold to the perception of threat. In turn, threat perception leads to activation of the SNS by the hypothalamus, modulated by noradrenalin and adrenalin.

Further understanding of the physical effects of stress are also seen in studies of immune responses where, as we will see below, cortisol again plays a crucial role.

# Individual differences in stress response

Not all people respond to environmental events in the same way. This may be for a number of factors. As noted in our critique of the basic Holmes and Rahe model, apparently similar events may carry very different meanings, some of which may be more or less benign or stress-engendering.

There is also the possibility that there are significant genetically mediated differences in our physiological responses to stress. Ellis et al. (2019), for example, argued that our genetic makeup influences the previously described neurobiological processes in response to both positive and negative life events. These genetic influences can be seen in variations in stress reactivity to adverse childhood experiences. For example, Boyce and colleagues (1995), presented two studies of naturally occurring environmental adversities and biological reactivity as predictors of respiratory illnesses in three- to five-year-old children. First, the results revealed that children showing low cardiovascular or immune reactivity to stressors had approximately equal rates of respiratory illnesses in both low and high adversity settings. Second, highly biologically reactive children exposed to high adversity child care settings or home environments had substantially higher illness incidences than all other groups of children. Third, the unexpected finding was that highly reactive children living in lower adversity conditions (i.e., more supportive child-care or family settings) had the *lowest* illness rates, which were significantly lower than even low reactivity children in comparable settings. However evidence from a longitudinal study of children and adolescents has offered little support for the concept of gene sensitivity moderating the effects of prior stressful life events on temperament change (Laceulle et al., 2014).

## Stress and immune function dysregulation

Declines or alterations in immune function have frequently been associated with the experience of stressful life events (e.g. Salovey et al., 2000; Ader, 2001; Glaser and Kiecolt-Glaser, 2005). Segestrom and Miller's review and meta-analysis of over 300 studies of stress and immune function confirmed that a relationship exists whether the stressor is acute, brief and naturalistic, a series of events, or chronic (Segestrom and Miller, 2004) and therefore some understanding of the processes through which this may occur is important.

As described in Chapter 8 ☛, the immune system is the body's defence against disease. Beyond the physical barrier of the skin, our bodies comprise of multiple levels of defence against antigens (foreign organisms such as bacteria, poisons, viruses, parasites), for example mechanical or chemical defences in our gut, our saliva, our noses and throat. Our defence against internal pathogens such as abnormal cells (e.g. cancer cells) relies on cells within our blood circulation and our lymphatic systems. Antigen threat can be met by either a general and rapid-response first line of defence (natural immunity), or a slower, more specifically targeted defence (specific immunity).

Immune cells are white blood cells of two major types, lymphocytes and phagocytes, which can be found in the lymphatic system, in the lymph nodes, spleen and in the blood circulation. The second of these, phagocytes, are attracted to sites of infection due to tissue releasing chemical messengers, and when they reach their destination they destroy abnormal cells or antigens by engulfing and consuming them. Phagocytes offer *non-specific immunity* in a first general line of defence, whereas lymphocytes offer *specific immunity* which follows the first natural responses. This consists of *cell-mediated immunity* via lymphocyte action which involves T cells made in the thymus (CD4+ T cells or helper T cells, and CD8+ cells or cytoxic T cells) and also *humoral*-mediated immunity involving B cells (memory and plasma cells), the actions of which are described in Chapter 8 ☛. B cells label invading antigens and cleverly, 'remember' them which enables early detection of future attacks. Specific and acquired immunity is provided by B and T cells whereas non-specific natural immunity against a wide variety of antigens is offered by a third type of cell, natural killer (NK) cells, which also occur in the blood/plasma. NK cells slow down the growth of abnormal cells, in cancer, for example, so that other immune responses can form an attack. (see Table 11.4 for a summary of T and B cell roles). Both the natural and the specific systems, involving NK, B and T

**Table 11.4** Specific immunity and cell types

| Humoral immunity: B cells | Cell-mediated immunity: T cells |
|---|---|
| Operate in the bloodstream | Operate at level of the cell |
| Work by releasing antibodies, which then destroy the antigen | Include memory, killer (NK), helper (CD4+) and suppressor T cells |
| Include memory cells | Mature in the thymus and not the bone marrow as other white blood cells do |

cells, interact and help one another in the fight against infection or abnormal cell growth (see Chapter 8 ☛ for further details of cell action, and for consideration of some conditions associated with 'faulty' immune system function, i.e. diabetes, rheumatoid arthritis, multiple sclerosis).

Therefore, the immune system is affected by the workings of the sympathetic nervous system and the endocrine responses and it is now generally accepted that there is communication both within and between the neuroendocrine and immune systems, with the brain providing an immuno-regulatory role. What is important here is that studies have found a link between the proliferation of B, T and NK cells and the subjective experience of stress; in other words, they have shown that psychological stress interferes with the workings of our body. One early study by Kiecolt-Glaser et al. (1984) found a significant reduction in NK cell activity among students prior to important end-of-term exams compared with those tested in mid-term. In addition, those students who reported feelings of loneliness plus a high number of recent stressful life events showed significantly less NK cell activity at both times than those students who were low in life events and low in loneliness. The findings of such experimental studies took a long time to be accepted, because they necessitated a paradigm shift from where the body was thought to operate independently of the mind to acceptance of the fact that psychological factors could influence immuno-competence (i.e. the degree to which our immune system functions effectively). Since this early work, there has been consistent evidence that stress can negatively impact on a wide range of bodily processes including wound healing, vaccination response, and the progression of immune-mediated diseases processes such as AIDS. Such is the subtlety of these findings that Ayling et al. (2018) found that a positive mood on the day of influenza vaccination can enhance the impact of the vaccine, while a 15-minute mood elevation protocol prior to vaccination also achieved modest gains in immunity against some strains of the flu virus (Ayling et al., 2019). Using a somewhat longer protocol, Broadbent et al. (2012) found that teaching relaxation and guided positive imagery over a period of 3 days resulted in significantly improved wound healing (using a measure of hydroxypoline – an amino acid involved in building the fibrinogen strands central to the regeneration of skin) following gallbladder removal surgery compared to a control group. Of note is that this improvement was achieved despite participants in the intervention group experiencing no subjective difference in stress to those in the control group.

## Age and immune function

It is generally accepted that immune function declines with age. This is sometimes referred to as 'immuno-senescence' whereby the innate system of an immediate immune response to invading germs, and also the slower-acting immune resistance response, declines (Gomez et al., 2008; Fali, Vallet and Sauce, 2018). There is evidence, from animal and human studies, suggesting that NK cell function becomes less efficient even though they are increased in number in older people, and that pro-inflammatory cytokine activity, which contributes to a wide range of age-related conditions, is increased (Ventura et al., 2017). The importance of these findings lies in the fact that they place older people at greater risk of severe reactions to infections, as seen in the influenza mortality statistics, for example, or in the complications of inflammation following wounds or surgery and slower healing. As an example of this research, Vedhara and colleagues in Bristol (Vedhara et al., 2003) examined the healing rates of foot ulcers among 60 adults with type 2 diabetes and found that healing was reduced in those who had shown high anxiety, depression or stress. Similarly, Broadbent et al. (2003) found impairing effects of high stress and worry levels on wound healing among those recovering from hernia surgery. Studies of caregivers also reveal significant associations, with caregivers of people with Alzheimer's disease, for example, showing slower wound healing than age-matched non-caregivers, and reduced antibody responses to immunisation (Damjanovic et al., 2007; Pederson-Fischer et al., 2009) (see also Chapter 15 ☛).

A review of 22 studies, including a meta-analysis of 11 of those studies, confirmed a relationship between psychological stress and healing of a range of wound types (Walburn et al., 2009). In fact, the role of stress in mediating wound healing has been unequivocally determined though animal, clinical and intervention studies (Broadbent and Koschwanez, 2012).

More generally, Graham et al.'s (2006) review suggested that in young adults stress can mimic the effects of ageing, and in older adults stress can exaggerate the effects of ageing on immune competence.

**Photo 11.3** Stress has been shown to influence the healing process

*Source*: Pheelings media/Shutterstock.

## Stress and cardiovascular reactivity

There is a reasonably consistent body of psychobiological evidence showing that stress can cause varied alterations in physiological responses, with the arousal of the sympathetic nervous system *and* deactivation of the parasympathetic response (see Brindle et al.'s 2014 review) being greater in some people than in others. This 'reactivity hypothesis' first proposed by Krantz and Manuck (1984) describes how genetic or environmental factors combine to influence a person's vulnerability to a physiological response following stress and to negative emotions that can be detrimental to their health, particularly their arterial health, implicated in heart disease. Reactivity, for example periods of elevated heart rate or blood pressure, has been observed both in laboratory settings where individuals are exposed to acute or repeated stress, such as mental arithmetic tasks or public speaking, and in real-life settings where people face occupational challenge or marital conflict, for example. There are some pointers towards ethnic variations in reactivity, for example, that African Americans tend to show greater reactivity where Asian or European Americans may not, although whether this is biologically or environmentally explained remains unclear.

Whether or not CVR (cardiovascular reactivity) is related to the development of disease, or indeed disease progression, is also something of great interest to psychobiologists and psychologists alike (e.g. Brindle et al., 2014; Pan et al., 2015). It does now appear that such reactivity is associated with risk for coronary heart disease (see below for more details), although the mechanisms are far from simple and are likely to involve a range of brain mechanisms (e.g. Ginty et al., 2017) as well as the more mechanistic processes involving damage and repair of blood vessel walls and changes in risk for clot development (see Chapter 8 ☛). The whole process of physiological arousal, from before an event (e.g. anticipatory responses, anxiety), during (as suggested by reactivity work), and after, in terms of perseverative thoughts or ruminative responses that may maintain physiological changes, warrants further attention (Bajko et al., 2012; Brosschot et al., 2006). Reactivity, which is thought to occur during an event (laboratory or real-life stressor), is perhaps only part of the physiological story, given also findings that under-activation can be harmful also (Brindle et al., 2014).

## Objective measures of stress

Evidence of the influence of psychological stress upon immune function, or upon cardiovascular reactivity has given scientists the opportunity to assess 'objective' indices of the stress response alongside, and in relation to, subjective stress reports. In terms of the stress of transient hassles, levels of cortisol were found to be higher among commuters experiencing unpredicted delays (Evans et al., 2002). In terms of chronic stress, Clays et al. (2007) found that ambulatory blood pressure at work, home and even while asleep was significantly higher in workers with high job strain than in those with lower strain. And in terms of effects over time, V. Burns et al. (2003) examined the effects of minor and major life events on the antibody response to influenza vaccination among a sample of undergraduate student and found that participants with low antibody levels when re-assessed after five months reported having experienced significantly more life events in the intervening time following vaccination.

Students are often used as participants in stress research due to the 'occupational hazard' of exposure to potentially stressful patterns of assessment and examinations! Chandrashekara et al. (2007), for example, found that medical students with high anxiety and poorer emotional adaptability about end-of-term exams showed lower levels of an inflammatory cytokine (tumour necrosis factor alpha – TNF-$\alpha$) than students with lower anxiety and greater emotional adaptability. The effect was not seen for mid-term exams. Such situation-specific responses contrasts with other findings where exposure to non-academic stressors contributed to a delayed *increase* in circulating cytokine levels (Steptoe et al., 2001). More research on these responses is warranted, particularly studies which contrast stressor types and contexts, as well as consider other individual difference variables that may contribute to stress reactivity (see Chapter 12 ☛). Importantly, it appears that extreme cardiovascular responses at either end of the spectrum, i.e. blunted or exaggerated, signal system dysregulation that can negatively impact upon health and behavioural outcomes (Lovallo, 2011). In terms of the implications of such findings for psychological intervention (see Chapter 13 ☛), there is increasing evidence that interventions designed to reduce stress (including relaxation, mindfulness, imagery, and cognitive behaviour therapy) can achieve modest but consistent benefits in term of in vitro measures of cytokine and NK cell production as well as measures of wound healing and vaccination response (Shakel et al., 2019).

It should have become clear during the course of this chapter that stress is not a unitary process but a highly complex one. The experience of stress is, to varying degrees, dependent on stimulus events (acute or chronic, physical or psychological), on internal representations of events, including a person's appraisals and emotional responses, and on the nature and extent of physiological and behavioural activation that follows. Stress indisputably has a strong psychological component, and furthermore stress responses change over time as a person adjusts (or not) to their situation. Given all the evidence reviewed above, it is hardly surprising that measuring stress is complex, as described in ISSUES below.

**ISSUES**

## Can stress be measured?

As with any concept, how stress is defined influences how it is measured. We have described three broad ways of thinking about stress – as a stimulus, as the result of cognitive appraisal and as a physiological response – and each of these views leads to different forms of assessment.

Measuring stress as a stimulus is problematic, given what was described earlier as weaknesses in the life events approach to stress – if many of the life events are irrelevant to the responder because of their age or life stage, does this mean that they are less stressed because their potential total scores are reduced? Additionally, people generally search for explanations for how they feel or for events that have happened to them – it is common, for example, for people to report many life events in the lead up to a heart attack – so measuring retrospective accounts of life events or even smaller 'hassles' may in this instance lead to inflated estimates of the role that stress plays in illness. Some researchers argue for greater validity of measures, taking a daily hassles (and uplifts) approach rather than a time-lagged retrospective. However, daily assessment places many demands on respondents, and in fact reviews of findings from studies using a life events approach has found the SSRS to have good predictive utility in terms of stress-related symptoms (Scully et al., 2000).

Stress is based upon appraisal, which involves stimulus, cognition and emotion, and therefore it is necessary to measure, not only the events, but also people's appraisals of the event, their emotions, their perceived resources and their perceived coping potential. Stress appraisals tend to be assessed by simply asking people how they feel or getting them to complete a standardised psychometric assessment. One commonly employed example is the Perceived Stress Scale, which assesses the degree to which life situations are appraised as stressful (Cohen et al., 1983). Examples include:

- 'In the last month, how often have you been upset because of something that happened unexpectedly?'
- 'In the last month, how often have you found that you could not cope with all the things you had to do?'

(scored as 0 = never; 1 = almost never; 2 = sometimes; 3 = fairly often; 4 = very often). Higher scores are indicative of greater perceived stress. The stressor, or the event being considered, is not specified, thus general appraisals are assessed only. Some studies, however, do reword the PSS to record event-specific stress appraisals, e.g. 'In the 2 weeks since receiving your diagnosis ...'.

Assessment of the secondary appraisal processes central to Lazarus's model, or of personal resources such as perceived control, self-efficacy or perceived social support, are plentiful. These factors, which are thought to moderate, mediate or 'buffer' the stress–outcome relationship, are described in Chapter 12 ☛. Regardless of the number of assessment tools used, however, there are inherent limitations in assessing subjective stress experiences. For example, distress is likely to bias the answers one gives to questions about the nature of the stressor, or about the number of recent life events experienced, and is also likely to influence the resources one consider oneself to have available. Stress is also quite circular – our mood and appraisals may increase our feelings of stress, which in turn will influence our appraisals and our mood! As aspects of the stress experience interact, research studies need well-designed, well-controlled longitudinal studies if they are to disentangle precursors of a stress response from the stress response itself.

In terms of assessing individual responses considered to be indicative of stress, studies commonly employ a measure of distress or more specific mood states (e.g. anger, depression or anxiety). One frequently used example is the general health questionnaire (GHQ; Goldberg and Williams, 1988) available in different validated lengths. The 28-item version measures a combination of emotional states (anxiety, insomnia, social dysfunction, severe depression and somatic symptoms), whereas the more common, and perhaps more user-friendly in terms of time demands, 12-item version does not distinguish between each of these, although it still provides a sensitive measure of psychiatric disorder. Example items include:

Have you recently ...

- been able to concentrate on whatever you're doing?
- been feeling unhappy and depressed? ...
- felt constantly under strain?'.

Respondents indicate whether they have experienced the stated item 'less than usual', 'no more than usual', 'rather more than usual' or 'much more than usual'.

As already described in this chapter, stress as a response can be measured using physiological and physical indices such as heart rate, blood pressure, galvanic skin response, levels of adrenaline, noradrenaline and cortisol levels in the blood, urine, or saliva, other indicators of increased cortisol levels such as reflected decreases in salivary secretory immunoglobulins (Sig-A), or other immune responses such as counts of helper T cells, B or NK cell activity. Measurement of these require specific skills and expertise in relation to their collection, storage, analysis and interpretation. As a consequence these are more often gathered in laboratory-based stress research than perhaps in naturalistic settings, although ambulatory measures of blood pressure or heart rate are available.

However, even so-called 'objective' measures of stress are open to question, however, as some people may simply be more 'stress-responsive' or 'stress-reactive' than others when exposed to the same stimulus (Felsten, 2004; Johnston, 2007). In other words, the extent of heart-rate or blood-pressure increase seen in response to threat is not universal, due to genetic differences, variations in central nervous system activity (Lovallo, 2011), individual differences in appraisal or emotion as those described earlier , or other moderators which are presented in Chapter 12 ☛.

In spite of challenges of measurement, a vast amount of research is conducted in this field that acknowledges that since stress is a subjective experience, measuring it cannot be expected to be an exact science. As Kasl (1996: 21) stated: 'What we have, at best, are indirect and partial indicators of the stress process, and these indicators tend to measure both too much and not enough'. As an illustration of this, he refers to the perceived stress scale, which measures 'too much' in that it correlates significantly with depression and measures 'not enough' in that it does not assess secondary appraisal processes, emotions or indicators of physiological reactivity. It is hard to satisfy all the needs of 'sufficient' assessment in the stress domain. Many empirical research studies have however acknowledged the challenge and employ multiple methods of assessment. This has consequent costs in terms of participant demands and potentially response rates therefore a challenge to researchers is in deciding which part of the picture to examine!

The final challenge in the domain of stress research is that of establishing causality between stressful events and illness, ideally via immune or other physiological pathways. In the final section of this chapter therefore we introduce you to some of the evidence of such associations.

# The stress and illness link

In Chapter 8 ☛, the workings of the nervous, respiratory, digestive, cardiovascular and immunological systems were described in some detail and the reader was introduced to common diseases associated with these bodily systems. In this final section we examine the role of stress in activating these systems with resulting implications for the development of illness. First, however, it is worth reminding ourselves that there are different ways of viewing the relationship between stress and illness.

## The direct route

Stress can produce physiological changes as described above that may lead to the development of illness, particularly in instances where the stress is chronic. However, there is so much individual variation in responding to stressors that the direct route is not a straightforward one, as reviewed below.

## The indirect routes

There are several indirect routes:

- People, by virtue of their behavioural responses to stress such as smoking, eating habits and drinking, predispose themselves to disease (see Chapter 3 ☛).
- People, by virtue of certain personality traits, predispose themselves to disease by the manner in which they respond to stress (see Chapter 12 ☛).
- People experiencing stress are more likely to use health services than people who are not under stress. Stress can produce symptoms such as anxiety, fatigue, insomnia and shakiness, for which people may seek treatment but which are not in themselves illnesses (see Chapter 12 ☛).

However, we should bear in mind a quote of Sapolsky's while reading the next sections: 'everything bad in human health now is not caused by stress, nor is it in our power to cure ourselves of our worst medical nightmares merely by reducing stress and thinking healthy thoughts full of courage and spirit and love. Would it were so. And shame on those who sell this view' (1994).

One explanation of how stress may indirectly lead to illness is when 'wear and tear' resulting from chronic or repeated stress occurs. This has been described by McEwen (2008) as 'allostatic load'. The process of 'allostasis' (coined by Sterling and Eyer, 1988) denotes the physiological responses and adaptation that are made following changes in our environment (e.g. noise, heat, overcrowding) or in our own physical states (due to illness, for example), in order to return us to a sense of balance, or homeostasis. Where these processes are overloaded, or challenged due to repeated acute stressors perhaps or fail to shut off as we fail to adapt to chronic stress, the systems fail and 'allostatic load' occurs. Importantly, it is the stress response that is creating the illness here, NOT the initial stressor, and in this regard psychological, behavioural and social factors also play a role. Increased or dysregulated allostasis, referred to by McEwen as being 'stressed out' can indirectly lead to illness by virtue of behavioural and physiological responses to this state: e.g. health-damaging behaviour such as smoking, excessive comfort eating, sleep loss (e.g. Segestrom and Miller, 2004). For a discussion of studies exploring physiological stress responses, including allostatic load, among child or adolescent samples, see Turner-Cobb (2014: 121–131).

There is a moderate relationship between stress and illness, and below we address a selection of the many illnesses that have been found to have an association with stress. The psychosocial influences upon, or moderators of, the stress response are then discussed in Chapter 12 ☛.

## Stress and the common cold

Many experiments have been conducted whereby volunteers (typically healthy adults) submit themselves to artificial exposure to respiratory rhinoviruses of the common cold (using nasal drops mainly) (Cohen et al., 1993a, 1993b, 1998; Stone et al., 1993; Cohen, 2005; Janicki-Deverts, Cohen and Doyle, 2016). Participants then remain in a controlled environment for varying lengths of time while researchers wait to see whether colds or infections develop more often among those who received viral drops than among the control subjects, who received saline drops. Typically, volunteers who had reported more chronic negative life events, perceived stress, negative affect and poor coping responses prior to the experiment were more likely to develop signs of respiratory infection and subsequent colds than both control subjects and experimental subjects with low-level life stress. In Cohen's studies perceived stress and negative affect predicted infection rates, whereas negative life events did not predict infection itself but predicted the probability of illness among those who became infected. Importantly, these associations persisted when health behaviour such as smoking and alcohol consumption or personality variables such as self-esteem and introversion–extroversion were controlled for (Cohen et al., 2003). More recently, Deverts and colleagues (Janicki-Deverts et al., 2016) found that perceived stress or social support did not directly increase the likelihood of adult participants experimentally exposed to a virus becoming ill. However clear moderating or buffering effects of other factors were seen; firstly where participants perceived stress and also reported negative affect, an increased risk of viral illness was seen regardless of the reported levels of social support; secondly participants who reported stress and high positive affect were less likely to develop illness if they also reported high levels of perceived social support.

As we will describe in Chapter 12 ☛, many factors interact within the relationship between stress and illness, as these experimental studies have shown.

Although the studies above were predominantly lab-based using artificially induced viruses, there is reasonably convincing evidence of a relationship between chronic stress (as opposed to severity) and upper respiratory infections – the common cold, and influenza (Takkouche et al., 2001; Marsland et al., 2002). Takkouche and colleagues importantly considered the naturally acquired common cold in a one-year prospective cohort study among the faculty and staff of a Spanish university (N = 1,149). Like the laboratory-based work before it, they found that the occurrence of stressful life events, perceived stress, and positive and negative affect were all related to the occurrence of common cold. Prospective studies with clinical populations facing 'natural' stressors will inevitably improve our understanding of the stress–immune function–illness link.

## Stress and coronary heart disease

Coronary heart disease (CHD) (or ischaemic heart disease (IHD) as it is also known) is a disease of the **cardiovascular** system that develops over time in response to a range of factors, such as family history and lifestyle factors (e.g. smoking and diet) (see Chapter 3 ☛). As described in Chapter 8 ☛, the cause of CHD is a gradual narrowing of blood vessels that supply the heart.

### Acute stress

In situations of acute stress, activation of the sympathetic nervous system causes increased cardiac output and the blood vessels to constrict, thus restricting blood flow, so blood pressure increases. This can cause damage to the artery walls, a process that is contributed to further by stress-induced adrenaline and noradrenaline output. In terms of processes by which this may be achieved, other studies have found that among those with pre-existing CVD, an acute stressor – for example, an anger outburst, or a depressive episode – may trigger the rupture of atherosclerotic plaques, which disrupt blood flow and cause a heart attack or a stroke (Sheps, 2007).

Cardiovascular reactivity during acute stress (i.e. increased heart rate or blood pressure) has been implicated in various disease processes, such as the extent and progression of carotid artery atherosclerosis, and the emergence of coronary heart disease itself (Smith et al., 2003). Reactivity, however, in itself is not 'disease', but a risk factor (Johnston, 2007). Experimental studies of reactivity in response to aversive or rewarding stimuli have speculated that individuals who responded to aversive tasks with sizeable heart-rate and blood pressure increases (high reactives) but who showed no difference from controls in subjective ratings of the tasks, had greater activation of the hypothalamic system and neuroendocrine responses such as those described earlier. Indeed, high-reactive participants showed larger noradrenaline increases in response to both types of task than low-reactive participants, and larger cortisol increases to the aversive task but not to the reward task (Lovallo et al., 1990). This highlights the importance of considering the type of task.

Also important is finding that effects persist beyond the artificial laboratory setting, as found, for example,

cardiovascular

pertaining to the heart and blood vessels.

by Johnston and colleagues (Johnston, 2007). In this study laboratory-based reactivity was reflected in similar increases in heart-rate reactivity when individuals were exposed to the real-life stressor of public speaking.

## Chronic stress

There is some evidence of a causal role for stress reactivity, inflammatory responses, and also negative emotions (depression primarily) in relation to acute coronary events and to CHD.

If blood pressure remains raised for prolonged periods of time, a person is said to have hypertension, a contributory factor in CHD. Repeated or chronic stress also activates the sympathetic nervous system's release of fatty acids into the bloodstream, which, if not utilised for energy expenditure, are metabolised by the liver into cholesterol. A build-up of cholesterol is highly implicated in the 'furring up' of arteries or atheroma (the laying down of fatty plaques on artery walls), and a key feature of heart disease is this atherosclerosis. Furthermore, the release of catecholamines during the stress process also increases the stickiness of blood platelets (thrombocytes), which elevates the risk of a clot forming or thrombosis as they adhere to the artery walls with the fatty plaques, thus making the 'passageway' even narrower for blood to flow through. Inflammatory processes, involving pro-inflammatory cytokines such as IL-6 (interleukin-6), are also implicated in this process (see Chapter 12 ☛ in relation to hostility). If reduced blood flow causes a clot to form, it could then travel through a person's arteries until it becomes so big as to form a blockage (occlusion) and, depending on whether it blocks an artery to the brain or to the heart, this will lead to either a stroke or a heart attack – both major causes of mortality worldwide (see Chapter 1 ☛) . In terms of acute coronary syndromes such as heart attack and stroke, the evidence that stress plays a role in precipitating the event is reasonably strong and accumulating, although not without its problems. For example, work and home stress, financial problems and past year major life events were significantly associated with heart attack in a huge cross-cultural, 52-country study of more than 11,000 heart attack survivors and over 13,000 controls, the INTER-HEART study (Rosengren et al., 2004). In a response to these data, however, Macleod et al. (2005) noted that these data were not replicated in their prospective study (Macleod et al. 2002) and that the cross-sectional design of the INTER-HEART study, involving interviews with patients very soon after experiencing a myocardial infarction, may have led to biased recall of stress and control prior to their hospitalisation.

Furthermore, in relation to ongoing stress of an occupational nature, job strain was linked to progression of coronary atherosclerosis over a three-year period in a large sample of women employees (Wang et al., 2007). In another study, ambulatory blood pressure at work and at home (and even while asleep!) was significantly higher in workers with high job strain than in those with lower strain (Clays et al., 2007). However the findings are inconsistent, for example, Kuper and Marmot (2003) found, within a cohort of over 10,000 UK civil servants, that those with low decision latitude and high demands were at the highest risk of developing CHD over 11 years, whereas an American study with a ten-year follow-up found no association between job strain and CHD (Eaker et al., 2004). A review of studies (including those two referred to above) with long-term follow-ups ranging from 5 to almost 20 years (Byrne and Espnes, 2008) suggests that overall findings are persuasive, but that more rigorous and prospective research is required.

Stress does appear to contribute to various precursors of heart disease, such as hypertension which showed an increased risk among those with anxiety when the data from 8 prospective studies was reviewed and meta-analysed (Pan et al., 2015), elevated serum lipids (fats in the blood) and smoking behaviour, an acknowledged risk factor (e.g. Ming et al., 2004). Although there is a preponderance of data supporting a general stress-disease hypothesis, there are some exceptions. In their meta-analysis, Sparrenberger et al. (2009), for example, found that acute life events were associated with hypertension in only one of three relevant studies, while five out of seven studies found an association between chronic stress and hypertension, with risk ratios varying from 0.8 (e.g. marginally lower risk if high chronic stress) to an eleven-fold increase in risk.

Overall, current findings point to a need to distinguish between the role stress plays in triggering or maintaining certain risk behaviours which provide the 'indirect' link with chronic manifestations of CHD, e.g. smoking and arterial disease; the role chronic stress plays in the activation of physiological risk factors and in progression of existing disease; and the role played perhaps by more acute stress events in the potentiating of acute coronary events, such as heart attacks (Johnston 2002, 2007; Strike and Steptoe, 2005; Sheps, 2007).

Finally, just as reactivity can be considered as a 'psychophysiological trait' that is stable within any given individual across time and events, it can also be considered as a moderator, in that evidence suggests that being reactive or not will moderate any effect of stress upon disease risk (Segerstrom and Smith, 2006). As will be discussed in Chapter 12 ☛, stress reactivity can itself be influenced by other traits, such as anger, and therefore it needs considered within a broader personological model. However reactivity is considered, it is a factor that seems unwise to ignore – we accept nowadays that the mind and body interact! If, into this picture we add individual 'risk' or 'protective' behaviours (see Chapters 3 and 4 ☛), we can begin to understand the complexity of influences upon disease processes such as those subsumed under the broad heading of 'heart disease'.

## Stress and cancer

Cancer, like heart disease, develops slowly and begins with mutation of cells and the development of generally undetectable neoplasms, which eventually develop into spreadable tumours (i.e. the cells metastasise). Predominantly animal research has demonstrated associations between environmental stressors (electric shocks, surgery) and increased susceptibility to tumour development; however, human evidence is limited. Forms of cancer vary hugely in terms of rates of growth, spread and prognosis; in terms of their sensitivity to neuroendocrine or immune system changes, and in terms of available treatment options, thus it is perhaps unwise to expect life event stress to exert uniform effects. This is illustrated in a review of reviews and meta-analysis of the relationship between psychological stress, cancer risk and cellular ageing, (Kruk et al., 2019) who report small associations between life events and cancer incidence in several cancer types, for example 5 of 9 reviews found an association between life events and increased breast cancer risk, although they report more consistent relationships between stress and cancer progression than initial cancer risk. Chiriac's review (Chiriac, Baban and Dumitrascu, 2018) also found a positive association between stressful events, personal traits and breast cancer incidence in 26/52 studies but notably also negative associations in 18 studies and non-classifiable effects in 8 studies. Jia and colleagues review of 25 studies found a 15 per cent increased risk of cancer overall, a 20 per cent increased risk of liver cancer and a 33 per cent increased risk of lung cancer in those with depression, but no relationship with breast, prostate or colorectal cancer (Jia et al., 2017).

In terms of life events and progression, Palesh et al. (2007) presented data from 94 women with metastatic or recurrent breast cancer tumours and found that those with no retrospective reports of traumatic life events, or lesser stressful events, had a significantly longer disease-free interval than women with experience of traumatic events, or of stressful events (median of 62 months as compared to median of 31 months). The women who had experienced traumatic events, or lesser stressful events, did not significantly differ from those reporting no stress events in terms of current age, age at diagnosis, medical history, relationship status, cortisol levels, site of metastases, and disease status indicators that may have offered alternative explanations for the findings. It is worth noting, however, that the reported events had not necessarily occurred in the intervening time period (i.e. between first diagnosis and recurrence) and therefore some had potentially played a role in the initial cancer. The authors had hypothesised that the mechanisms through which stress exerted any effect on recurrence was likely to relate to HPA function, yet cortisol measurements did not differ between groups. This study is of course limited by its retrospective nature and challenged by the findings of a five-year prospective study of women diagnosed with breast cancer where recurrence was not increased in those who had experienced one or more extremely stressful events in the year prior to diagnosis or in the five years subsequently (Graham et al., 2002). This latter finding is more robust: it involves a larger sample of women, is prospective in nature, and more clearly controls for biological prognostic indicators such as tumour size and the extent to which the cancer involved the lymph nodes.

The effects of stress appear to be more in relation to cancer progression, rather than in its onset (e.g. Chida et al., 2008; Lutgendorf and Sood, 2011; Cancer Research UK, 2021). With regards to more intrinsic influences, the role of the individual and their cognitive, emotional and coping responses there is some evidence of direct and indirect effects on cancer progression. For example, the stress response may directly affect tumour cell mutation by slowing down the cell repair process, possibly by virtue of stress effects on hormonal activation and the release of glucocorticoids, or by influences on the immune system's production of lymphocytes.

Many other studies have explored whether personality, coping style (particularly one that is passive and indicative of helplessness and hopelessness) and mood affect cancer outcome and have provoked some controversy. These are addressed in Chapter 12 ☛.

## Stress and bowel disease

Two diseases of the bowel have been investigated in terms of their association with stress, whereby stress is examined as an exacerbating factor rather than one involved in illness development (see also Chapter 8 ☛). First, irritable bowel syndrome (IBS) is a disorder of the lower large intestine characterised by abdominal pain and prolonged periods of either diarrhoea or constipation, with no obvious underlying physical cause identifiable. During stressful episodes, the reactivity of the gut is greater and symptoms such as increased bloatedness, pain or diarrhoea may be maintained by stress or anxiety (Naliboff et al., 1998; Spence and Moss-Morris, 2007). Although IBS symptoms are linked to factors such as infection in the gut, a strong relationship is also seen between its symptoms and stress. Spence and Moss-Morris (2007), for example, found that patients with gastroenteritis were more likely to develop IBS if they scored highly on measures of perceived stress, anxiety, and somatisation. Similarly, Riddle et al. (2016) found that US military personnel with new-onset IBS differed from those without the disorder on measures of pre-IBS gastric symptoms, gender (female increased risk of IBS), number of life stressors, anxiety and depression. Levels of on-going stress also appear to moderate its outcome once established. Bennett et al. (1998), for example, followed a cohort of 117 patients with IBS, and found that chronic life stress predicted 97 per cent of symptom intensity between baseline and 16-month follow-up. No one exposed to even one chronic highly threatening stressor made clinically significant improvements over the 16 months of the study.

A second bowel disease is *inflammatory bowel disease* (IBD), which can be subdivided into Crohn's disease (CD) and ulcerative colitis (UC). Both these diseases are typified by pain and diarrhoea, which fluctuate in an alternating and disruptive manner. UC typically involves inflammation of the lower colon, whereas CD can occur anywhere in the gastrointestinal tract and is seen as inflammation of the outer intestinal wall.

Both diseases, as with IBS, were originally thought have no underlying physical pathology and to be psychosomatic with some limited evidence that stress plays a role in their aetiology. There is also some evidence that stress is associated with symptom exacerbation; although not as strongly or immediately as perhaps initially thought. Guthrie (2007) noted that only three out of seven studies exploring this issue, found a relationship between psychosocial baseline measures and symptom exacerbation, including one study which followed a cohort of patients in remission from UC for up to 45 months (Levenstein et al., 2000). High levels of stress reported for the two years prior to taking part in the study significantly increased risk for exacerbation and mucosal abnormalities during the study- however, exacerbation was not associated with the experience of stressful life events, depressive symptoms, or high levels of perceived stress experienced during the follow-up period. Subsequently, Mittermaier et al. (2014) followed 60 patients with inactive IBD over a period of 18 months, measuring a range of psychological and physical measures every three months. Over this time, 59 per cent of the sample experienced a further episode of IBD. Regression analysis showed a significant association between depression (and to a lesser extent anxiety) at baseline and the total number of relapses reported at 12- and 18-months follow-up, however, again, no association was found between perceived stress during the follow-up period and IBD symptomatology.

## Stress and HIV/AIDS

AIDS (acquired immune deficiency syndrome) is a syndrome characterised by opportunistic infections and other malignant diseases and fundamentally acquisition of the HIV (human immunodeficiency virus) which was first identified in 1984 can compromise a person's immune system (see Chapter 8 ☛). Crucially, in terms of potential stress for the sufferer, as a slow-acting virus (i.e. a lentivirus), it can be many years before an HIV-infected individual develops AIDS. The robust treatment for HIV infection (see Chapter 8 ☛) which can prolong life and reduce levels of the virus to be literally unmeasurable, means the role of stress in the disease course and outcomes are perhaps less pragmatically important than in the past. Nevertheless, studies of the impact of stress on markers of HIV progression provide interesting insights into how stress affects at least parts of the immune system.

Overall, stress makes a difference. In a review and meta-analysis of the relevant literature, Chida and Vedhara (2009), for example, concluded that there was a modest relationship between a range of stress-related psychological factors including personality types, coping styles, and psychological distress on markers as varied as time to develop AIDS andCD4+ cell count decline and disease progression. The impact of distress and experience of stress was less than that of personality and coping strategies, but nevertheless was significant. The role of depression is also important, perhaps more so than stress. In one study of this relationship, Farinpour et al. (2003) reported the findings of a 13-year follow-up study of over 1,000 HIV-positive individuals and found general intellectual functioning, age, and somatic symptoms of depression to be significant predictors of HIV disease progression and survival even after controlling for baseline disease severity and medication use. In a subsequent review of eight studies conducted between 2015 and 2019, Yousuf et al. (2019) found similar findings. They also noted that levels of depression were consistently higher than those of anxiety in the study populations, further emphasising the importance of measuring depression. Showing the subtlety of some of these issues, an early meta-analysis by Zorrilla et al. (1996) suggested that depressive symptoms, but not stress experience, were associated with increased speed of symptom onset in HIV-positive individuals, and that stress, but not depressive symptoms, was associated with reduced NK cell count.

## SUMMARY

This chapter set out to provide a definition of stress in order to show that there is no such thing as a simple definition! Stress is generally examined in one of three ways: as a stimulus that focuses on the external event (stressors); as a transaction between the external event and the individual experiencing it; and as an array of physiological responses that are manifested when an individual faces demanding events. The transactional psychological model of stress highlights the crucial role of appraisal, and points to the importance of considering the individual in the stress experience. Many different events may be appraised as stressful; stressor events can be acute or chronic in their manifestation and the responses they require highly variable. We provided examples of these, drawing both from studies of occupational stress, something that most of us will experience at some time, and of chronic health conditions (which many of us will also experience at some point!). The physiological pathways by which stress has been shown to affect health status were examined. While some evidence of a direct effect of stress on the development of illness exists, many of stress's effects are either indirect, for example via an influence on behaviour, or are more evident during the illness experience, when individual differences in personality, cognitions and social resources become important to outcome. These moderating variables are the focus of the next chapter.

## Further reading

Sapolsky, R.M. (2004). *Why Zebras Don't Get Ulcers*. New York: Henry Holt & Co.

Although dated in terms of empirical material covered, this remains an engaging read with excellent coverage of both physiological and psychological *theories* of stress. You will, however, need to supplement reading of this book with up-to-date empirical studies!

Ader, R. (2007). *Psychoneuroimmunology*, 4th edn. New York: Academic Press.

Written for an interdisciplinary audience including behavioural scientists, psychobiologists, neuroscientists and immunologists, this book is an accessible (not overly hardcore biology) review of the field and the fundamental science of psychoneuroimmunology (the processes, mechanisms and effects of behavioural, neural, endocrine and immune responses).

O'Connor, D.B., Thayer, J.F., and Vedhara, K. (2021). Stress and health: a review of psychobiological processes, *Annual Review of Psychology*, 72: 663–88. doi.org/10.1146/annurev-psych-062520-122331

This paper provides a nicely up-to-date review of lab and real-world evidence of the effects of stress on biological systems such as described in this chapter and highlights the importance of considering stress in the context of physical health

Anisman, H. (2014). *An Introduction to Stress and Health*. London: Sage.

This very useful and informed book addresses the psychosocial aspects of stress but particularly focuses on the (neuro) biological correlates of stress and their association with physical health conditions, emotional wellbeing and mood.

Byrne, D.G. and Espnes, G.A. (2008). Occupational stress and cardiovascular disease. *Stress & Health*, 24: 231–8.

This review paper is found in a special issue addressing ‘Stress and the Heart’. It reviews evidence of the role played by work stress and coronary risk, hypertension and heart disease and concludes that ‘Taken broadly, the evidence is supportive of postulated links’, although further prospective evidence would be welcome.

www.stressinamerica.org

This useful website, although drawing from annual USA surveys of Stress, describes and presents a wealth of material relevant to this and the subsequent chapter in terms of: changing life pressures and stress, responses to stress and how they differ by age, gender, or even whether a parent or not; the effects of stress on health behaviours such as drinking or smoking, and also factors that moderate stress, such as social support (see also Chapter 12 ☛).

# Chapter 12

# Stress and illness moderators

## Learning outcomes

By the end of this chapter, you should have an understanding of:

- coping theory, definitions and the distinction between coping styles, strategies and goals
- how coping responses influence the manner in which stress may affect health outcomes
- aspects of personality which influence stress appraisal, coping response and illness outcomes
- aspects of individual cognitions which influence stress appraisal, coping response and illness outcomes
- aspects of emotion, which influence stress appraisal, coping response and illness outcomes
- the nature and function of social support and how it influences stress appraisal, coping responses and illness outcomes

## It’s not just our gut that has a biome

Nourishment does not just come from the food we eat, which enters the gut biome. According to Jeffery Hall, from the University of Kansas, in conversation with the *Guardian* in 2021, we also take in ‘nourishment’ from our social interactions with others: our social biome (*The Guardian*, 2021). According to Hall, a healthy biome, and therefore a mentally healthy individual, has multiple levels of social interactions, from casual conversations with colleagues, deep and meaningful conversations with close friends, to interactions on social media. He suggests that the health of our social biome is as important, if not more important, than the gut biome. Hall notes that there is consistent evidence that physical health or even the risk of dying is linked to the number and quality of friendships an individual has. More immediately, mental health is closely linked to our social interactions, with more frequent and longer ‘meaningful’ interactions being linked to higher levels of wellbeing. That said, it’s also good to have ‘alone time’ as part of a healthy social biome; essentially it’s a combination of healthy social interactions and having the choice to take alone time that has the optimal associations with mental and physical health.

As this chapter will show, many factors influence our response to stress and our coping ability, but being socially connected plays a significant role regardless of age, gender, culture or context, with effects not only on emotional wellbeing but potentially, as we will report below, physical wellbeing.

## Chapter outline

**The preceding chapter established that stress can be considered as both an objective and subjective experience, with evidence provided as to the physiological and immunological pathways through which stress can influence health and illness status. However, not all people will become ill when exposed to stressful events. This raises questions of great fascination to health psychologists – what aspects of the individual, their stress responses, or their stress-coping resources and actions influence the negative impact of stress on health? This chapter will provide some answers to this question by providing evidence of psychosocial influences on stress outcomes. Individual differences in personality, cognitions and emotions (both positive and negative) have direct and indirect effects on stress outcomes. Indirectly, they affect outcome by influencing our cognitive and behavioural responses to any stressful demand placed on us – these responses are known as coping. In addition, aspects of social relationships and social support act as external resource variables, which also directly and indirectly influence the negative impact of stress. By the end of the chapter, the complexities of the relationship between stress, health and illness should be clear.**

In Chapter 11 ☛ we described stress theories, acute and chronic stressors and the broad theoretical links between stress and disease. We also presented evidence relating to direct pathways by which physiological and immune processes can affect the stress–disease relationship. However, there is much individual variation in responding to stressors, and so this chapter focuses on those factors that make the stress-illness relationship more indirect i.e. how different personalities, beliefs and emotions, and social relationships influence the stress–illness relationship, via an effect on physiological responses, or on cognitive and behavioural coping responses.

It is unlikely that anyone can avoid stress and, certainly, as indicated previously, some stress is good for us in that it enhances performance (eustress e.g. Gibbons et al., 2008). However, stress is more commonly considered as negative appraisals and negative emotions, as introduced in the previous chapter in relation to Lazarus's transactional model of stress and coping (Lazarus, 1966; Lazarus and Folkman, 1984). When negative thoughts or emotions arise we would typically want to reduce them in order to restore a sense of harmony or balance in our lives. Crucially, individual differences in appraisal influences the cognitive, emotional and behavioural response made, i.e. the coping response. What exactly do we mean by coping?

## Coping defined

Although over thirty definitions of coping exist, Lazarus's transactional model (see Figure 11.1 ☛) has had the most profound impact on the conceptualisation of coping (cf. Lazarus, 1993a, 1993b; Lazarus and Folkman, 1984). This is a generic model of stress and coping, whereas in Chapter 9 ☛ we described a model of coping specific to the self-regulation of illness experience and consequent to illness perceptions.

According to Lazarus's model, psychological stress results from an unfavourable person–environment fit: in other words, when there is a perceived mismatch between demands and resources as perceived by an individual in a specific situation (Lazarus and Folkman, 1984; Lazarus, 1993a). Individuals are required to alter either the stressor or how they interpret it in order to make it appear more favourable. This volitional (purposeful) effort is called coping. Coping involves a constellation of cognitions and behaviour that arise from the primary and secondary appraisals of events, and the emotions attached to them (see Chapter 11 ☛). In turn, our appraisals are influenced by many factors, not least of which is the extent to which we perceive the event as interfering with our personal life goals (e.g. to succeed in school, to avoid conflict, to be independent; Elliot et al., 2011).

Coping is *anything* a person does to reduce the impact of a perceived or actual stressor, and, because appraisals elicit emotions, coping can operate to either alter or reduce the negative emotions, or it can directly target the 'objective' stressor. Coping therefore is volitional because it has the aim of trying to achieve adaptation: it is consequently a dynamic, learned (we hopefully learn from past coping successes and failures) and purposeful process.

Cohen and Lazarus (1979) described five main coping functions, each of which contribute to successful adaptation to a stressor:

1. reducing harmful external conditions;
2. tolerating or adjusting to negative events;
3. maintaining a positive self-image;
4. maintaining emotional equilibrium and decreasing emotional stress;
5. maintaining a satisfactory relationship with the environment or with others.

Coping does not therefore inevitably eliminate the stressor, but it may manage the stressor by various means: for example, through mastering new skills to deal with it, tolerating it, reappraising it or minimising it.

Coping can be cognitive or behavioural, active or passive, with many different, often overlapping, terms being used in the coping literature. Two of the main taxonomies are summarised in Table 12.1: firstly, those which differentiate between problem-focused and emotion-focused coping (cf. Folkman and Lazarus, 1980, 1985); and secondly those which distinguish between approach-oriented coping and avoidance (cf. Roth and Cohen, 1986; Suls and Fletcher, 1985).

Within each of the broad dimensions described in Table 12.1 are a variety of coping subscales, generally derived from **factor analysis** of a large number of coping items in an attempt to identify statistically meaningful 'clusters' of items that can then be used in a new measurement scale.

**factor analysis**
a method of analysis which seeks to reduce relationships between a wide set of correlated items into meaningful groups, or factors.

**Table 12.1** Coping dimensions

1. **Problem-focused coping (problem-solving function)**, i.e. instrumental coping efforts (cognitive and/or behavioural) directed at the stressor in order to either reduce the demands of it or increase one's resources. Strategies include: planning how to change the stressor or how to behave in order to control it; suppressing competing activities in order to focus on ways of dealing with the stressor; seeking practical or informational support in order to alter the stressor; confronting the source of stress; or showing restraint.

   +/or

   **Emotion-focused coping (emotion-regulating function)**, i.e. mainly, but not solely, cognitive coping efforts directed at managing the emotional response to the stressor: for example, positively reappraising the stressor in order to see it in a more positive light; acceptance; seeking emotional support; venting anger; praying.
2. **Attentional/approach, monitoring, vigilant, active,** i.e. concerned with attending to the source of stress and trying to deal with the problem by, for example, seeking information about it, or making active cognitive or behavioural efforts to manage the stressor (see also coping styles).

   +/or

   **Avoidant, blunting, passive,** i.e. concerned with avoiding or minimising the threat of the stressor; sometimes emotion-focused, sometimes involves avoiding the actual situation: for example, distraction by thinking of pleasant thoughts or distraction by engaging in other activities to keep one's mind off the stressor; disengagement through substance use.

Folkman and Lazarus (1988), in the popular Ways of Coping scale, distinguished eight subscales that address the two dimensions of problem-focused and emotion-focused coping: confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape–avoidance, planned problem solving and positive reappraisal. Carver and colleagues (1989), in their COPE measure, identified 13, and subsequently 15, subscales: planning, active coping, suppressing competing activities, acceptance, turning to religion, venting emotions, seeking instrumental support, seeking emotional support, humour, positive reinterpretation, restraint coping, denial, mental disengagement, behavioural disengagement, alcohol or drug use. In contrast, Endler and colleagues (Endler and Parker, 1993; Endler et al., 1998) assessed across three dimensions: emotion-oriented (person-oriented strategies such as daydreaming, emotional response or self-preoccupation); task-oriented (strategies to solve, minimise or reconceptualise the problem) and avoidance-oriented (includes distraction or social diversion (CISS scale)). In contrast to situational specific coping 'strategies', Krohne (1993) proposed that vigilance and cognitive avoidance responses were two coping 'superstrategies' on orthogonal dimensions of attention orientation which were likely to reflect underlying personality, has led to considerations of coping 'style'.

## Coping styles or strategies

Coping styles are generally considered as unrelated to the specific context or stressor stimulus; instead, they are trait-like forms of coping that people have a tendency to adopt when facing a potentially difficult situation. If you think about your own behaviour, you will probably know whether you tend to duck and avoid stressors or whether you face them head-on! Indicating a general tendency towards a particular style of coping rather than one led by particular features of a situation, Bennett et al. (2012) found that the coping responses used by women undergoing assessment of their genetic risk for breast cancer and facing a range of issues including fear of cancer, hospitalisation, telling their family, waiting for results, completing the genetic testing questionnaire, tended to rely on the same strategies.

One example of a coping style dimension is that of 'monitoring versus blunting' (Miller, 1987; Miller et al., 1987). Monitoring reflects an approach style of coping, where threat-relevant information is sought out and processed, for example, asking about treatments and side effects, or seeking information about forthcoming exam content. Blunting reflects a general tendency to avoid or distract oneself from threat-relevant information, such as by sleeping or daydreaming, or engaging in other activities to avoid thinking about forthcoming exams. Illustrating this, Rood et al. (2015) examined the coping style and quality of life of patients diagnosed with various blood cancers. As predicted, patients with a monitoring coping style had higher needs for both general and specific information about their condition and a wish to be involved in decision-making. They also reported lower levels of satisfaction with the information they were given. By contrast, blunting was linked to lower levels of need for information. Of note also was that quality of life was independent of coping style. These findings were consistent with a wider review (Roussi and Miller, 2014) of 63 separate studies of monitoring and blunting among those at risk of, or diagnosed with, cancer, where results revealed that although monitoring increased a person's knowledge of the health threat faced, they experienced lower information satisfaction, greater perceived risk and higher negative affect. The conflicting outcomes of a monitoring style of coping highlights the importance of context – a person's coping style may not 'fit' the situation and as a result may be counter-adaptive. This is where the adoption of situation-specific coping strategies is important.

Coping in a certain way will not be universally effective or ineffective (Taylor and Stanton, 2008) as it very much depends on the 'goodness of fit' between the situation and the coping response selected (Chapter 11 ☛). Even the same apparent stressor may evoke different coping strategies at different times. For example, after failing a driving test the first time it may be useful to engage in active coping responses such as practicing particular manoevres more, however if you failed again a second or a third time (as I did!) it may be more helpful to focus more on managing your emotions during the test so as not to affect your performance.

Coping strategies (see Table 12.1 for examples of commonly employed coping subscales) derive from an approach that considers stress and coping as a dynamic process that varies according to context, event and the person's personal goals, resources, mood, and so on as we describe in this chapter (see Figure 12.1). Coping at any one time might include a range of seemingly oppositional strategies, i.e it is not the case that a person may cope solely in a problem-focused way. Preparation for exams may include both spending time revising

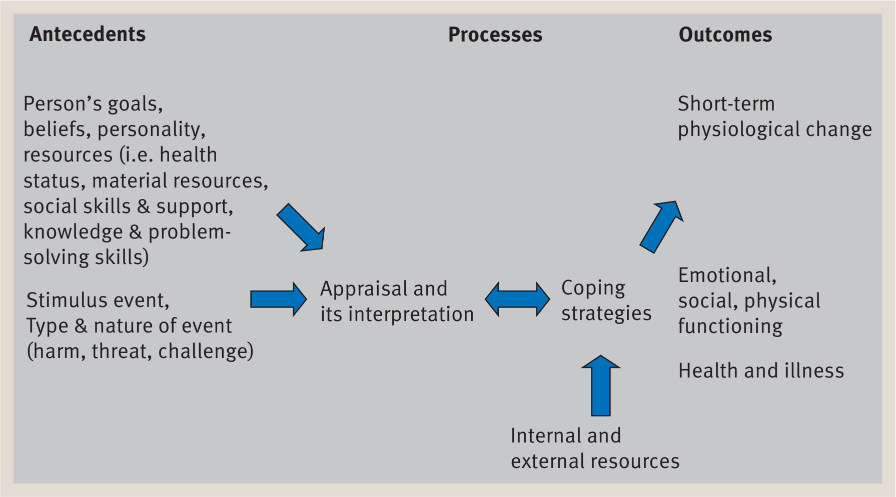


**Figure 12.1** The coping process

*Source*: Adapted from Lazarus (1999: 198).

(problem-focused coping) and going to the pub to distract from worrying about it for a time (emotion-focused coping). Similarly illustrating this Lowe et al. (2000) found that in the months following a heart attack, people used both passive coping (e.g. acceptance, positive reappraisal) and active, **problem-focused coping** simultaneously. Also, in a rarely studied population of people aged over 85 years old living in the community (i.e. not in institutions), Johnson and Barer (1997) found that both acceptance of change (in oneself cf. dependency) as well as disengagement from stressful roles were common. This study also highlighted that for the oldest-old, giving up some control was beneficial, whereas studies of the younger-old find that fighting to retain aspects of self and independence are common (Rothermund and Brandstädter, 2003).

At the other end of the age spectrum, a review of 58 studies of coping that examined age effects on coping strategies, discerned two kinds of age trends (Zimmer-Gembeck and Skinner, 2011). Firstly, an increase in coping capacity was observed with support-seeking coping responses moving from a reliance on adults to more self-reliance, problem-solving coping becoming less based on instrumental action and becoming more planned problem-solving, and distraction coping (including cognitive as well as behavioural strategies). Secondly, increased age was seen to associate with changes in coping deployment with improvements seen in coping flexibility and tailoring of coping strategy to specific kinds of stressors.

While coping research in the field of health psychology more commonly assesses coping strategies than styles, the two approaches can be addressed simultaneously. For example, studies adopting repeated assessment periods can examine the nature and consistency of coping strategies over time, and provide evidence of repeated and consistent use of specific strategies suggesting a 'style' of coping (e.g. Tennen et al., 2000).

## What is adaptive coping?

Generally, it is considered that problem-focused approach or attentional coping is more likely to be adaptive when there is something that can be done to alter or control the stressor event. Focusing one's thoughts on aspects of the situation and planning how to deal with each would be an example of a cognitive problem-focused coping strategy, whereas seeking helpful information about the event would be a behavioural problem-focused coping strategy. Behavioural examples of **emotion-focused coping** include venting and displaying emotion or seeking emotional support. This latter strategy is generally considered to be adaptive.

**problem-focused coping**
coping that seeks to reduce the demands of the stressor or increase one's resources to deal with it.

**emotion-focused coping**
coping that seeks to manage the emotional response to the stressor.

## Being responsive

Lazarus's model of coping suggests that it is hard to predict which coping strategies will be effective in which situations, as both problem-focused and emotion-focused strategies are interdependent and work together to create the overall coping response in any situation (Lazarus, 1993b). Tennen et al. (2000) confirmed this in an impressive longitudinal study of pain patients where daily measures of coping were taken. They found that emotion-focused coping strategies were 4.4 times more likely to be used on a day when problem-focused strategies were also used than on days where problem-focused strategies were not used. They also report that day-to-day pain symptomatology influenced the daily coping strategies used: for example, 'an increase in pain over yesterday's pain increased the likelihood that problem-focused coping yesterday would be followed by emotion-focused coping today' (p. 632). This highlights the role of appraisal and reappraisal of coping efforts: modifications are made depending on whether previous coping efforts are thought to have been successful or not. Troy et al. (2010) further highlighted the critical role of cognitive reappraisal as a means of emotional regulation, i.e. regulating the emotional coping (such as getting upset or venting anger) that often exists in situations of high stress. They found that at high, but not low, levels of stress, women with high cognitive reappraisal ability experienced fewer depressive symptoms than those low in this ability. This individual difference factor may explain why in highly stressful situations some people appear to adjust emotionally better than others (see later section for further discussion of such (di)stress moderators).

## Coping flexibility

Coping is highly contextual – to be effective it has to be amenable to change (see Figure 11.1 in the previous chapter ☛, where there are arrows feeding back from coping to (re) appraisal, and also Figure 12.1). If the stressor event is starting a new job and this is eliciting anxiety, coping can either deal with the 'job' (make contacts with new colleagues, research the company and its products), or it can deal with the anxiety (engage in meditation, talk with a friend, get drunk). As noted already, the person may in fact cope in various ways and do all of the above. It should not be assumed that coping in a way which addresses the problem directly (researching the new role) is inherently more adaptive than coping which does not (talking to a friend). Maintaining distinctions between emotion-focused and problem-focused coping is sometimes difficult, as movement between them is ever-present.

Individuals who are typically problem-focused, vigilant or attentional in their coping with stress may find that in some circumstances this is counter-productive. For example, when receiving a diagnosis of a life-threatening illness emotion-focused coping may be more adaptive because in such events the individual has little control. For example, the cognitive emotion-focused coping strategy of denial was found to be an effective coping response among women with a recent breast cancer diagnosis by Greer et al. (1990) although ongoing denial was associated with poorer 15-year survival outcomes, suggesting that denial may have a good 'fit' to the situation in the short- but not long-term. Extending these findings further, a review of children coping with cancer found that in the first 6–12 months following diagnosis, approach coping (a control-oriented, problem-focused coping) was associated with poorer adjustment, whereas it predicted better adjustment when patients were 5–6 years after diagnosis (Aldridge and Roesch, 2007). Further supporting possible time and context dependent effects of avoidant coping, Cohee et al. (2021) found that the use of avoidant (emotion-focused) coping was significantly associated with higher levels of distress among women who had recovered from cancer treatment and were considered cancer survivors. The more they used avoidant coping as a means of dealing with fears of recurrence and body image concerns, the higher their levels of anxiety. It may be that an alternative approach, emotional approach coping would have benefitted here, at least in relation to the first of these womens' concerns.

## Emotional-approach coping

Stanton et al. (2000) have pointed out that emotions can have adaptive coping functions rather than the disruptive functions often implied in the emotion-focused coping distinction. In a series of studies, they examined 'emotional-approach coping' and distinguished between 'emotional processing' (active attempts to understand the emotions experienced) and 'emotional expression' (see also later section) with both forms of coping considered to involve active and positive psychological adjustment. In support of this, positive reappraisal of one's responses to an event (e.g. 'It could have been worse, at least I did my best') can elicit positive emotion (e.g. pride, satisfaction) (Fredrickson, 2001; Folkman and Moskowitz, 2004). Positive emotions in turn, according to Fredrickson, 'broaden' what a person feels like doing at that time, i.e. it expands their desired possibilities, whereas negative emotions shut off our thinking of possibilities, and also 'build' our resources, whether they be psychological, physical, social or intellectual, for example building problem-solving skills, new bonds, alternative goals or adaptive-coping responses. This upward spiral of positive emotions is also called the 'broaden and build model' of positive emotions (Cohn and Fredrickson, 2009) (see Figure 12.2).

As well as positive emotions, positive coping responses have also been identified. One potentially exciting finding, at least in its early exploration, was a response to cancer termed 'fighting spirit' (e.g. 'I am determined to beat this disease') which was found to be associated with improved outcomes and long-term survival among breast cancer patients (Greer et al., 1990). In contrast, feelings of hopelessness and helplessness (e.g. 'I feel there is nothing I can do to help myself') were associated with poorer survival among this same population (M. Watson et al., 1999a) and among stroke patients (Lewis et al., 2001). These coping responses of fighting spirit and helplessness differentially associated with either active, problem-focused or passive, **avoidant coping** behaviour. Fighting spirit was thought to reflect a kind of realistic optimism and determination, with people high in fighting spirit facing illness head-on rather than avoiding it (Spiegel, 2001). These early findings elicited hope for interventions that could enhance disease outcomes by targeting such attitudes and coping responses: for example, increasing fighting spirit while decreasing feelings of helplessness. However, a review and meta-analysis of 26 studies investigating the effects of fighting spirit or hopelessness/helplessness and cancer survival or recurrence concluded that many of the reported predictive associations between these variables were undermined by small sample sizes or poor methodological quality (Petticrew et al., 2002). Furthermore, a later ten-year follow-up of 578 women with early-stage breast cancer conducted by the original research team also failed to replicate long-term predictive associations for fighting spirit, although helpless/hopelessness coping remained predictive of survival outcome (Watson et al., 2005). Despite these disappointing findings, the concept should perhaps not be abandoned. It may not impact on disease outcomes, but fighting spirit appears to benefit quality of life, and helplessness-hopelessness is associated with emotional distress in cancer patients (see Allart, Suobeyran and Cousson-Gelie, 2013). Are these constructs emotions linked to one's appraisals, or coping responses arising from one's appraisals and emotions- there are likely to be bi-directional relationships and thus the need for well designed, well controlled, prospective studies is clear.

avoidant coping

a style of coping that involves emotional regulation by avoiding confrontation with a stressful situation; analagous to emotion-focused coping.

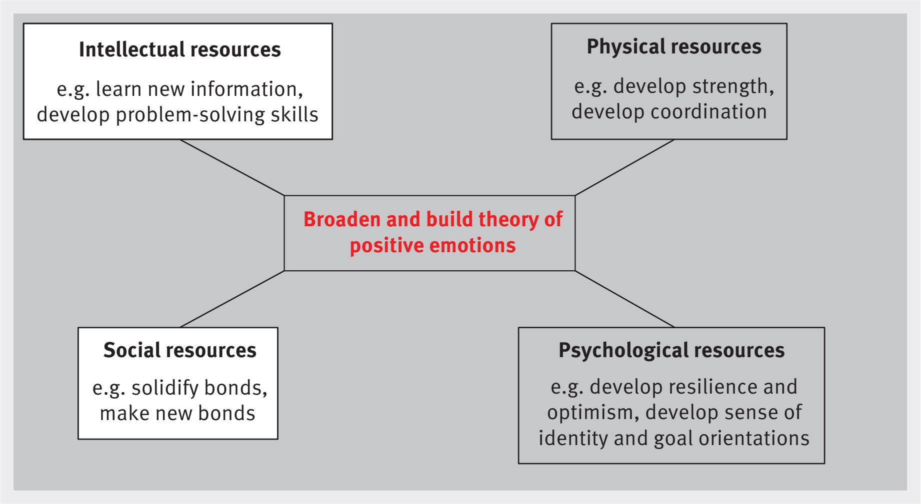


**Figure 12.2** The broaden and build theory of positive emotions

*Source*: Fredrickson, 2003, Sigma Xi, The Scientific Research honor Society.

### Meaning-focussed coping

Folkman and Moskowitch (2000) describe how stressful events can lead to more positive outcomes by virtue of appraisals and responses they describe as *meaning-focused coping,* or also *meaning-making* (Park and Folkman, 1997). Typified by coping strategies which draw on a person's values and beliefs and encompass goal revision, reordering of priorities and focusing on strengths in order to obtain personal and possibly existential meaning within a negative and stressful situation has seen a surge of research interest given growth in the field of positive psychogy (Seligman and Csikszentmihalyi, 2000). Meaning-focused coping was thought to regulate the experience of positive emotion, such as hope (Folkman, 2010), and is reflected in literature on benefit-finding, personal growth, and post-traumatic growth (see Chapter 14 ☛, and also Helgeson et al., 2006; Tedeschi and Calhoun, 2004, 2008). However, following findings from an admittedly small and select sample, it has been suggested (Baumeister et al., 2013) that a meaningful life is not necessarily a happier one! Research continues to explore whether there are in fact adaptational benefits to meaning-focused coping. A review of benefit-finding among cancer patients, and a review and meta-analysis of research into personal growth among those with cancer or HIV/AIDS have respectively reported associations with better immune functioning (Pascoe and Edvardsson, 2013), and better self-rated mental and physical health (Sawyer et al., 2010).

### WHAT DO YOU THINK?

Think of a recent stressful experience you have faced. What strategies did you adopt in order to deal with this event? What were you hoping to achieve through the use of these strategies? Would you describe some of the strategies you adopted as 'problem-focused' and others as 'emotion-focused' or did you rely on one form of coping only? If you tried several different strategies, did they each have a different goal and, if so, which were effective and which were not?

In revisiting that experience, can you think of anything in your personal background, your character or outlook on life that influenced how you responded to that event? Keep the experience you have just been thinking about in mind as you continue reading this chapter and consider whether any of the influences on stress and coping that we describe are relevant to how you dealt with that event in particular, or with stress generally.

## Coping goals

Coping intentions or goals (see Coyne and Racioppo, 2000) are likely to influence the coping strategies employed in any given situation and their likely success, although surprisingly few studies have explicitly addressed these. Coping goals, such as a desire to return to 'normalcy' after a trauma or while experiencing illness, have rarely been studied in relation to the specific strategies which are selected in an attempt to achieve that goal. Unless we know 'why' a person choses to cope in a particular way in terms of what they hoped to achieve – reduced distress, more support, less pain etc., etc. – we cannot tell whether or not that particular coping strategy has been effective. Coping success is defined by its' outcome. One reason for selecting one or more strategy to deal with a perceived stressor one's past experience with that coping response, and more importantly what the anticipated outcomes of that coping response are, i.e. coping is a purposeful or motivational process (Lazarus, 1993b). One of the few studies to explore his issue in detail was reported by Sorkin and Rook (2006) who explored community living older adults' coping goals, coping efforts and emotional responses with regards to unsuccessful social exchanges. Following such exchanges, the goals and outcomes differed markedly. Those participants whose coping goal was to change the interaction partner's behaviour were more likely to confront them and use assertion to achieve their goals, whereas those whose main goal was to achieve or maintain harmony responded with conciliatory responses and engaged in self-blame and forgiveness.

While these findings may appear obvious, they demonstrate that simply researching potential stressors and the coping responses to them misses out a major element of the response chain. People use different coping strategies, often simultaneously, perhaps because each one is aiming for a different goal. Some goals may be short-term (e.g. to avoid medication side effects so as to be able to go about one's daily routine) and others may be longer-term (e.g. to manage one's condition so as to achieve recovery) – the short-term goal here may reduce the very coping response of medication management that is necessary to achieve the second longer term goal (e.g. Pound et al., 2005). Conflicting demands of short and long-term goals can lead to what has been described as 'self-regulation failure' as seen in studies of nonadherence (considering adherence as a problem-focussed coping response). For example in the context of psoriasis management (a serious skin condition) adherence to the required application of visible skin creams was avoided by some study participants because it increased the likelihood of their engaging in social avoidance behaviours (Thorneloe et al., 2017). More research is needed to progress our understanding of coping goals- what influences them, how and why they may change over time, and how sometimes they may conflict, as this will also be beneficial to the shaping of interventions to optimise individuals' coping responses.

## Stress, personality and illness

What is personality? Personality can be defined as the 'dynamic organization within the individual of those psychophysical systems that determine his characteristic behavior and thought' (Allport, 1961: 28). This definition reflects a trait approach to personality (see also Chapter 5 ☛), which considers a person's personality profile in terms of stable and enduring dimensions such as sensitivity, conscientiousness or neuroticism. Personality traits provide a helpful means for us to typify behaviour patterns, with clusters of traits often providing 'typologies'; for example, an extroverted 'type' of person will generally exhibit sociable, adventurous and impulsive traits, while a psychotic 'type' will exhibit egocentric, aggressive, cold and impulsive characteristics (Eysenck, 1982). Note that impulsivity features in both 'types', yet overall the two types differ in terms of clustered traits.

As described in Chapter 5 ☛ Eysenck (1970, 1991) argued for two, and then three dimensions of personality- neuroticism and extroversion, with psychoticism added subsequently. However, decades of research has confirmed that five superordinate factors provided a better description of the structure of personality (see Wrosch and Scheier's overview, 2003) and thus, the model adopted most widely in health psychology is a five-factor model, often referred to as the 'Big Five' theory. This conceptualises and assesses personality using the following dimensions (McCrae and Costa, 1987, 1990; Costa and McCrae, 1992a, 1992b):

- agreeableness, i.e. cooperative, trusting, compliant;
- conscientiousness, i.e. responsible and striving;
- extroversion, i.e. positive, assertive, active, sociable;
- neuroticism, i.e. tense, anxious, pessimistic;
- openness, i.e. imaginative, curious, open to new experiences.

Each of these factors are superordinate traits which include various facets (see Costa and McCrae's 1992b measure, the NEO-FFI). Many associations between these relatively stable personality traits, stress, coping and health outcomes have been reported (see Vollrath, 2006; Semmer, 2006) with many studies examining the traits separately as we shall see below. How can we explain these associations? Various possible models of association have been proposed, offering differing degrees of 'directness':

- Personality may simply be predictive of disease onset (e.g. Friedman and Booth-Kewley, 1987) although we will see below how much of this is questioned. This is the notion of a generic 'disease-prone personality' which underpins the psychosomatic tradition.
- Specific clusters of personality traits may predispose to specific illnesses (e.g. **Type A behaviour** pattern and heart disease, Type C and cancer, see later section). One likely route of such effects is physiological: for example, angry personalities may be more physiologically stress-reactive (see Chapter 11 ☛). Thus, this route is indirect.
- Personality may promote unhealthy behaviour predictive of disease (e.g. low conscientiousness and excessive alcohol intake, see Figure 12.3), thereby having an indirect effect on disease risk (e.g. Bogg and Roberts, 2004; O'Connor et al., 2009) (see Chapters 3 and 5 ☛).
- Aspects of personality may influence the manner in which an individual appraises or copes with stress or illness events (e.g. neurotic individuals may over-attend to the stressor; stress may be more damaging for those low in conscientiousness), thereby having an indirect effect on illness progression or outcomes (e.g. Penley and Tomaka, 2002; Ferguson, 2013).

**Type A behaviour (TAB)**

a constellation of characteristics, mannerisms and behaviour including competitiveness, time urgency, impatience, easily aroused hostility, rapid and vigorous speech patterns and expressive behaviour; extensively studied in relation to the aetiology of coronary heart disease, where hostility seems central.

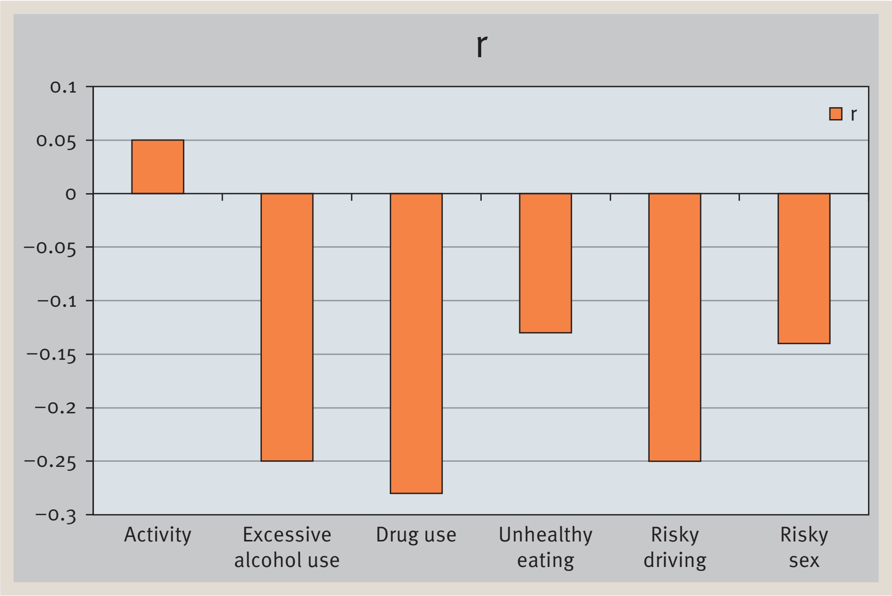


**Figure 12.3** Conscientiousness and selected health behaviours. The average correlation between conscientiousness and selected health behaviours, meta-analysis. NB The number of studies and sample N included for each behaviour differed, ranging from 14 studies of unhealthy eating (N 6,356), to 65 studies of excessive alcohol use (N 32, 137)

*Source*: Adapted from Bogg and Roberts (2004: 908).

Studies employing five-factor models have typically found that each has differential associations with health behaviour (see also Chapter 5 ☛ ; e.g. Nicholson et al., 2005), symptom perception (Cameron and Leventhal, 2003), coping (e.g. Cooper et al., 2000) and illness behaviour (e.g. Korotkov and Hannah, 2004), with inconsistent findings seen in relation to chronic morbidity or the ultimate health outcome, that of mortality (Heilmayr and Friedman, 2017). For example, a negative association, was found between conscientiousness and all-cause mortality in a large epidemiological study of over 76,000 individuals where 3,947 individual deaths were examined (Jokela et al., 2013), while in another meta-analysis, openness to experience was also a protective factor in relation to all-cause mortality (Ferguson and Bibby, 2012). A more recent meta-synthesis involving 36 meta-analyses and over half a million study participants, found, when examined separately, bigger associations with health outcomes for agreeableness, conscientiousness and neuroticism than for extroversion or openeness to experience, and when the Big Five traits were entered simultaneously only a moderate association with overall health was seen, with a stronger relationship with mental health than with physical health or health behaviours (Strickhouser, Zell and Krizan, 2017).

We outline below a few of the empirical findings relating to each of the Big Five traits.

## Neuroticism and negative affectivity

As one of the three personality dimensions identified by Eysenck (1982), and one of the 'Big Five', neuroticism (N) has received a lot of research attention in relation to stress and to illness. Trait N is a broad dimension considered to be relatively unchangeable and characterised by the tendency to experience negative emotions and to exhibit associated beliefs and behaviours, including withdrawal or apprehensiveness (Costa and McCrae, 1987; McCrae, 1990). Individuals high on neuroticism often display anxious beliefs and behaviour disproportionate to the situation (Suls and Martin, 2005, and see also Chapter 9 ☛ in terms of attention to internal states and increased somatic complaints). Related to neuroticism is a pervasive trait known as negative affectivity (NA), proposed by Watson and Clark (1984) to play a central role in the stress–health relationship. High-NA individuals are characterised by a generalised negative outlook, greater introspection, low affect (mood) and low self-concept. In studies of a range of adult samples, NA has been associated with lower self-rated health, greater health complaints, but generally not with objective ill-health indicators (Watson and Pennebaker, 1989; Cohen et al., 1995; Evers et al., 2003). However, the ultimate health indicator – death – was predicted by neuroticism in a 21-year prospective cohort of 5,424 UK adults, specifically death from cardiovascular diseases, even when controlling for known risk factors (Shipley et al., 2007). However in relation to cancer recurrence or survival outcomes neither neuroticism or extroversion were found to have an effect (e.g. Canada et al., 2005). Just to show how complicated things may be, Hagger-Johnson et al. (2012) found that high N increased risk for heart disease-related death in women in lower socio-economic groups but reduced the risk for such deaths among women from higher income groups. As in the Shipley study, this association was attenuated but not eradicated after controlling for health behaviours and was not found for men, or for deaths from cancer. One partial and plausible explanation for this could be N's effect on health-seeking behaviour, which also interacts with socio-economic status (see Chapter 9 ☛).

Another explanation for any relationships between N and negative outcomes may be that neurotics by virtue of their character have a heightened responsiveness to negative situations, e.g. work stress, and that this increases the degree of conflict experienced, which then increases the number of stressful events reported! This was reported in a 15-year follow-up study of work–family conflict carried out by Wille and colleagues (Wille et al., 2013). It is, however, hard to disentangle actual events from subjective reports of events, especially since most studies rely on self-report. In terms of responding to events appraised as stressful, neurotic individuals are commonly found to employ a greater variety of coping strategies (perhaps searching for one that works), although these tend to be maladaptive and emotion-focused coping strategies (see Semmer, 2006; Karimzade and Besharat, 2011).

Without fully understanding the mechanisms by which N and NA affect outcomes, these variables are sometimes described as 'nuisance factors' (Watson and Pennebaker, 1989: 248), whereby researchers interpret self-reported outcomes of health complaints, stress or distress, with caution, because any relationship 'found' between stress and illness may be inflated by reporting bias of participants high in N/NA. There is, however, some evidence that neuroticism and NA have a direct route to negative health outcomes via immune suppression. For example, NA has been associated with cortisol production (e.g. van Eck et al., 1996); and neuroticism associated with interleukin-6 (II-6) in older samples (e.g. Bouhuys et al., 2004). Given that stress has also been shown to have immune effects as we have described in Chapter 11 ☛, it may be that personality adds to this already negative relationship.

## Conscientiousness and the other Big Five traits

Conscientiousness (C), defined as being of a responsible and dependable character, following social norms, having foresight, being persistent and self-disciplined, has shown a consistent relationship to positive outcomes both in relation to stress and to health. Conscientious individuals may be more likely to problem-solve effectively, seek support and engage in cognitive restructuring factors useful in reducing work–life/family conflict, for example (Michel et al., 2011). In relation to health outcomes, a meta-analysis of 20 independent samples, representing child samples, middle-aged samples, as well as those with chronic disease, found a modest, but nonetheless significant correlation of 0.11 between C and longevity (Kern and Friedman, 2008), and conscientiousness was associated with reduced mortality risk in studies with long-term follow-up (Hagger-Johnson et al., 2012; Jokela et al., 2013). Two studies of centenarians also found conscientiousness to be protective (Masui et al., 2006; Martin et al., 2006). A more recent study of middle-aged individuals has both replicated these findings and found that one physiological pathway to longevity may involve low levels of inflammation as a consequence of low IL-6 titres (O'Súilleabháin et al., 2021).

This general effect across a range of samples and cultures is therefore notable and may be attributable to findings of fairly robust associations between conscientiousness and positive health behaviours (e.g. Bogg and Roberts, 2004 (see Figure 12.3 for a summary of their findings); Nicholson et al., 2005; O'Connor et al., 2009: Paunonen and Ashton, 2001), including medication adherence (Molloy et al., 2014) – thus providing an indirect link between personality and health or illness. In addition to influencing health behaviours, those high in conscientiousness have been shown to use problem-focused coping when responding to stress (Bartley and Roesch, 2011), and their characteristic persistence is considered beneficial to self-regulatory efforts, such as when trying to control one's response to stress (Hagger et al., 2010; Solberg Nes et al., 2011). It has also been suggested that while extraversion and neuroticism are more closely associated with emotional wellbeing (e.g. happiness), conscientiousness is more closely aligned to cognitive and evaluative aspects of wellbeing (e.g. satisfaction) (De Neve and Cooper, 1998; Hayes and Joseph, 2003).

Of the other 'Big Five' personality traits, agreeableness is generally considered adaptive in terms of increasing a person's flexibility of coping response, for example using affiliative skills to build social support networks known to be beneficial for an array of outcomes (see later). In relation to work–family conflict, agreeableness has been found both beneficial in some studies and not so in others (see Michel at al.'s 2011 review), suggesting that being agreeable to others may not always be in your own best interests perhaps! Extraversion, that tendency to have a positive and active attitude and behavioural style, has been found to be positive in some regards, e.g. appraisal, active coping, and emotional wellbeing (Hayes and Joseph, 2003), but, contrary to the study hypothesis was not significant in relation to work–life conflict (Wille et al., 2013), and was negatively associated with health-risk behaviours, given extroverts' tendency to seek stimulation (see Chapters 3 and 5 ☛). Positive associations have however also been reported between extroversion and use of both problem- and emotion-focused coping, suggesting flexibility in response to stress (e.g. Karimzade and Besharat, 2011). Extraversion has also emerged as protective for mortality generally among centenarians (Masui et al., 2006; Martin et al., 2006) and also for specifically respiratory-disease-related death (Shipley et al., 2007), possibly explained by enhanced immune function by way of increased Natural Killer cells (Bouhuys et al., 2004). These positive effects contradict associations with risk behaviours such as smoking; however, it is worth noting that Shipley's study controlled for such risk factors, and therefore the mechanism through which extraversion operates remains unclear.

In terms of personality and disease onset, findings also are mixed and vary depending upon the illness considered. Illustrating this, the large Health and Retirement Study which assessed the 'Big Five' traits at baseline among 6,904 older adults and then examined incidence of *new* onset of arthritis, cancer, diabetes, heart disease, hypertension, lung disease or stroke over the subsequent four years, found moderate associations only with arthritis, heart disease and stroke, and particularly for the traits of openness, consceientiousness and neuroticism (Weston, Hill and Jackson, 2014). Note however this is a sample also of older adults which limits the generalisability of findings to questions of predicting disease onset in other age groups.

Besides the Big Five, other factors have been identified that have 'general' positive effects on stress responses and health, and we turn attention now to these 'personal resource' variables.

## Optimism

One 'protective' resource is that of dispositional optimism, i.e. having a generally stable positive outlook and positive outcome expectations. Scheier and colleagues (Scheier et al., 1986; Scheier and Carver, 1992) proposed that dispositional optimists are predisposed towards believing that desired outcomes are possible, and that this motivates optimistic individuals to cope more effectively and persistently with stress or illness events, thus reducing their risk of negative outcomes. Dispositionally optimistic persons are less likely to make internal ('It is my fault'), stable ('It is an aspect of my personality that I cannot change') and global attributions for negative events: i.e. they are more likely to appraise stress as changeable and specific and coming from external sources that are potentially more changeable or ignorable than internal ones (see Table 12.2).

Optimism has been found to benefit both healthy populations dealing with stressful events (e.g. Steptoe et al., 2008) and patient populations dealing with various aspects of their illness (e.g. Fournier et al., 2002) and is also associated with healthy behaviours (e.g. Contrada and Goyal, 2005) which may themselves mediate such outcomes. High levels of optimism seem health protective, both in the long- and short-term. Ebrecht et al. (2004), for example, found optimism to be associated with faster healing of experimentally administered standardised wounds. Over the even longer term, Matthews et al. (2004) found that optimism was predictive of the progression of atherosclerosis in healthy women over a period of three years, after controlling for a range of potential confounding factors such as lifestyle and medication. Those with the highest levels of optimism showed almost no increase in atherosclerosis over this time. Impressively, even among adults aged 85 years and older, where you may expect physical factors to be dominant, optimism was still significantly associated with the likelihood of

**Table 12.2** Measuring optimism: the Life Orientation Test (Scheier, Carver and Bridges, 1994)

Please be as honest and accurate as you can be throughout. Try not to let your response to one statement influence your responses to other statements. There are no 'correct' or 'incorrect' answers. Answer according to your *own* feelings rather than how you think 'most people' would answer. Using the scale below, write the appropriate letter in the box beside each statement.

| | A I agree a lot | B I agree a little | C I neither agree nor disagree | D I disagree a little | E I disagree a lot |
|---|---|---|---|---|---|
| 1. In uncertain times, I usually expect the best | | | | | ☐ |
| 2. It's easy for me to relax* | | | | | ☐ |
| 3. If something can go wrong for me, it will | | | | | ☐ |
| 4. I always look on the bright side | | | | | ☐ |
| 5. I'm always optimistic about my future | | | | | ☐ |
| 6. I enjoy my friends a lot* | | | | | ☐ |
| 7. It's important for me to keep busy* | | | | | ☐ |
| 8. I hardly ever expect things to go my way | | | | | ☐ |
| 9. Things never work out the way I want them to | | | | | ☐ |
| 10. I don't get upset easily* | | | | | ☐ |
| 11. I'm a believer in the idea that 'every cloud has a silver lining' | | | | | ☐ |
| 12. I rarely count on good things happening to me | | | | | ☐ |

*These are 'filter' items, which have the function of disguising the focus of the test.

survival over a five-year period (Jacobs, Maaravi and Stessman, 2021). In an earlier review and meta-analysis of an impressive array of 84 studies optimism was associated with positive health outcomes including fewer physical symptoms, better immune function and lower risk of cardiovascular diseases (Rasmussen, Scheier and Greenhouse, 2009).

Pessimism, on the other hand, is a generalised and stable negative outlook associated with denial and distancing responses to stress. Pessimism among cancer patients, for example, was found to have independent effects to optimism and was associated with mortality among younger patients even when controlling for the related construct of depression (Schulz et al., 1996). Indeed, in a recent meta-analysis it appears the negative effects of pessimism may be stronger than the positive effects of optimism (Scheier et al., 2020).

What are the likely mechanisms to explain such associations?

- *Coping*: The benefits of optimism are likely to be a consequence of optimistic individuals' better management of stress, as seen in a meta-analysis where optimism was positively associated with approach coping and negatively associated with avoidance coping (Solberg Nes and Segestrom, 2006). As another example, optimism following cancer diagnosis predicted more positive adjustment in the subsequent 12 months, possibly by reducing disease-related threat appraisals and avoidant coping (Schou et al., 2005). Optimistic people expect positive outcomes and appraise events in a way that increases their likelihood of adopting problem-focused coping strategies, including perseverance. For example, students with optimistic expectations put in more effort and reported less distress in the run up to exams (Lench et al., 2021), although following a series of experimental studies Tenney (Tenney, Logg and Morre, 2015) concluded that increasing persistence does not necessarily improve performance! Where problem-focussed coping is not an option, they use adaptive emotion-focused coping strategies such as positive reframing, humour or acceptance (Wrosch and Scheier, 2003).
- *Behaviour*: We also know optimists engage in more healthy behaviours and less risky behaviours (Contrada and Goyal, 2005), possibly because they are optimistic about the potential benefits of behaving in such a manner (Scheier and Carver, 2018). Optimists also are shown to make use of social support (Contrada and Goyal, 2005).
- *Association with emotions*: The costs of pessimism may be associated with low mood, less healthy

behaviours and poorer coping mechanisms to handle stress.

- *Physiological routes*: At least one physiological mechanism appears to have been ruled out however given DuPont et al.'s (2020) meta-analysis findings where optimism was unexpectedly associated with enhanced (not decreased) cardiac reactivity to experimental cognitive stressors. However, optimistic individuals may have less inflammation and better immune responses as a consequence of their ability to manage stress.

Related to dispositional optimism is the construct of unrealistic optimism, i.e. the view that unpleasant events are more likely to happen to others than to oneself, and that pleasant events are more likely to happen to oneself than to others (Weinstein, 1982; see Chapter 5 ☛). Sometimes referred to as 'defensive optimism' (Schwarzer, 1994), this way of thinking may operate as an emotional buffer against the recognition or acceptance of possible negative outcomes, i.e. it may protect people from a depressing reality.

The effects of an optimistic disposition may, however, vary, depending on context and the controllability of the disease. Some have suggested that in controllable conditions, such as self-management of insulin-dependent diabetes, dispositional optimism is beneficial, whereas in less controllable conditions, such as multiple sclerosis, it is not (Fournier et al., 2002). However, others have found that higher optimism was associated with subsequent higher quality of life in a sample of 217 women in the terminal phases (last year of life) of ovarian cancer (Price et al., 2013). Such a finding may suggest that optimism is akin to denial in this context, with adaptive benefits in such an uncontrollable situation.

Another study suggests, however, that the beneficial effects of optimism may be more complex in chronically or multiply challenging situations. Solberg Nes et al. (2011) found that while there were beneficial effects of optimism on task persistence by those with chronic multi-symptom illness (and also control participants), the association was weakened when self-regulatory fatigue was experienced. Perhaps when facing multiple challenges to self-regulation and where 'self-regulatory fatigue' is present, optimism may struggle to maintain its positive influence. By persevering in trying to deal with a challenging situation, rather than disengaging, optimists may in fact risk their health, as also suggested by findings of reduced immune function in such situations (Soldberg Nes and Segerstrom, 2006; Segestrom, 2005). Further research is needed to explore these interesting findings.

**Photo 12.1** How optimistic are you? Is this glass half-empty or half-full?

*Source*: Tanya Louise Robinson.

Although generally considered to be a trait, and thus offering more limited opportunity for intervention than do situational cognitions such as perceived control, Folkman and Moskowitz (2000) have suggested that optimistic beliefs can be maintained by successful coping outcomes. This suggests that coping-skills training and positive feedback on successful efforts may build optimism. If so, optimism would then become closer to self-efficacy.

## Hardiness and resilience

When searching for factors that might differentiate those who respond to stress by becoming ill from those who stay healthy, Kobasa (1979, 1982) identified the protective effects of a belief system arising from a person having experienced rich, varied and rewarding experiences in childhood, and manifest in feelings of:

- *Commitment*: a person's sense of purpose or involvement in events, activities and with people in their lives. Committed individuals would view potentially stressful situations as meaningful and interesting.
- *Control*: a person's belief that they can influence events in their lives. Individuals high on control were thought to view stressors as potentially changeable.
- *Challenge*: a person's tendency to view change as a normal aspect of life and as something that can be positive. Individuals scoring high on the challenge dimension would view change as an opportunity for growth rather than as a threat to security.

Rather than exerting a direct effect on health, it is thought that by possessing each of these characteristics, a hardy person would be protected against the negative experience of stress, thus enabling them to remain healthy. In particular Kobasa reported that hardiness had more effect in situations of high stress than in situations of low stress, i.e. a 'buffering' effect. Cross-sectional findings of buffering effects of hardiness however were not consistently replicated in prospective studies, with some authors suggesting that a lack of hardiness is important, rather than the presence of it, and also that non-hardiness may reflect underlying trait neuroticism (Funk, 1992). Certainly there is a relationship between the two (see review by Semmer, 2006) and this was supported by Kowalski and Schermer (2019) who examined hardiness, coping and self-rated health among 258 adults in terms of it being negatively associated with neuroticism, rumination and worry (as discussed above, constructs typically associated with negative health outcomes). When controlling for neuroticism, the relationship between hardiness, coping, and health became nonsignificant, lending support to Funk and others' earlier criticisms. However even when controlling for neuroticim, hardiness remained significantly associated with indices of mental health, i.e. with low anxiety, worry and somatisation, suggesting that there remains room to consider hardiness as offering something additional to neuroticism.

Notably in this study the measure of hardiness was a dispositional resilience scale, and often these terms are used interchangeably. Resilience is defined as the ability to 'bounce back' in times of adversity, first identified in the 1980s by Smith (Werner and Smith, 1982, 1992) with two facets to those who 'bounced back' – an outgoing disposition, and an ability to access several sources of social support – possibly reflecting a sense of challenge and commitment as described in hardiness. Those considering resilience as a personality resource provide evidence of benefits to stress adaptation, positive psychological health and health outcomes (Smith, 2006), and even adolescent health behaviours (Mistry et al., 2009). However for both constructs, hardiness and resilience, questions remain as to whether they are fixed traits held by a person regardless of stress being present, or whether they emerge as resources only in times of stress. If the latter, then opportunities for intervention open up in terms of building a person's resource.

## Type A behaviour and personality

Coronary heart disease (CHD) and its outcomes (heart attack, angina, cardiac death) have been studied extensively in relation to personality variables and to emotion (see later section). The search for a coronary-prone personality led to the discovery of a constellation of behaviour labelled Type A behaviour (TAB) (Friedman and Rosenman, 1974; Rosenman, 1978; Rosenman, 1996). TAB is a multidimensional concept combining action and emotion (see Chapter 9 ☛ definition) and is manifest in individuals showing high levels of the following:

- day-to-day competitiveness;
- time-urgent behaviour (trying to do too much in too little time);
- easily annoyed/aroused hostility and anger;
- impatience;
- achievement-oriented behaviour;
- a 'vigorous' speech pattern characterised by being rapid, loud, tense and clipped, with much interrupting of others.

In the early work around this construct (1960s and 1970s), TAB was found to modestly but consistently increase the risk of CHD and MI (heart attack) mortality when compared with persons showing a Type B behaviour pattern (the converse of Type A, i.e. relaxed with little aggressive drive) (e.g. the Western Collaborative Group study (WCGS) – Rosenman et al. 1978; and the Framingham heart study – Haynes et al. 1980). However most subsequent research, including follow-up of the WCGS participants, have failed to confirm these early associations In fact, some of these studies found very different results to what was expected: for example, Ragland and Brand's (Ragland and Brand, 1988) 22-year follow-up of the WCGS cohort found that Type Bs with prior CHD experienced a second heart attack sooner than Type As with prior CHD, and healthy Type As were no more likely than healthy Type Bs to have experienced a fatal heart attack! Some of the contradictory findings may be explained by differences in the methods of assessment of TAB (for example, structured face-to-face interviews versus self-completed questionnaires) or by sampling differences (some studies used healthy samples, others used heart attack survivors or those with other risk factors, such as smoking). Or perhaps, as a meta-analysis of studies suggests (Myrtek, 2001), contradictory findings arise from differences in the heart disease outcome assessed (e.g. heart attack event, heart attack death, angina, arterial disease), with studies reporting positive findings predominantly using *self-reported angina* as the index of CHD, with obvious limitations.

While evidence of a TAB–coronary illness link may now be questioned, there is some evidence suggesting that Type As respond more quickly and in a stronger emotional manner to stress, and that they exhibit a greater need for control than non-Type A individuals – factors which may actually increase the person's likelihood of encountering stress by influencing their interactions with others (Smith, 1994). As described in Chapter 11 ☛, cardiovascular reactivity during stress has been implicated in various disease processes, such as the extent and progression of carotid artery atherosclerosis and the emergence of coronary heart disease (Smith et al., 2003; Pan et al., 2015). It is this reactivity that may provide the mechanism by which personality or Type A characteristics influence disease although several reviews of available research led more to the door of a particular behavioural component of the initially proposed Type A cluster- that of hostile attitudes and behaviour (e.g. T. Miller et al., 1996), exemplified by responses which endorsed items such as 'I have often met people who were supposed to be experts who were no better than I', or 'It is safer to trust nobody' on the Cook Medley Hostility Scale (see below). Type A research has all but been replaced by hostility and anger research.

## Hostility and anger

Investigations of the pathways through which hostility might be having effects led to exploration of several possible mechanisms:

1. Hostile individuals may be more likely to engage in health-risk behaviour which are risk factors for illnesses such as heart disease, for example excessive smoking or alcohol intake (Whiteman, 2006).
2. Hostile individuals have a lower capacity to benefit from psychosocial resources or interpersonal support and thus are less 'buffered' against the negative effects of stressful or challenging events (T. Miller et al., 1996). Described as a 'psychosocial vulnerability hypothesis', whereby hostility is considered to moderate the relationship between stressful environmental characteristics and health problems. Kivimäki et al.'s (2003) large-scale study of Finnish adults found that, for men only, hostility influenced the relationship between unemployment and ill-health, with hostile men having a high prevalence of health problems regardless of employment status, whereas non-hostile men had better health if employed.
3. Experimental studies suggest that hostile individuals are generally more stress-reactive than non-hostile individuals, rendering them physiologically vulnerable to coronary heart disease and acute events such as heart attack by virtue of heightened blood pressure of neuroendocrine responses when faced with a stressor (Fredrickson et al., 2000; Strike and Steptoe, 2005). For example, Everson et al. (1995) showed that individuals scoring high in hostility had increased cardiovascular activation during a task performed after a staged interruption and that, furthermore, hostile individuals differed in their evaluations of the experiment and the person who interrupted them than did low-hostility participants (e.g. they manifest more irritation and anger, and feelings of being personally insulted). As described in Chapter 11 ☛ prolonged or repeated episodes of elevated blood pressure may cause damage to the walls of vessels carrying blood to the heart (the coronary arteries).

Enough evidence was amassed from systematic reviews and meta-analyses to conclude that hostility is a likely risk factor for development of CHD, with several studies suggesting that the association is most evident in younger samples (aged 60 or under) or among men (e.g. Smith et al., 2003; and see Myrtek, 2001; Whiteman, 2006; Chida and Steptoe, 2009 for reviews). However, there have been inconsistencies in findings and so, similar to that which happened with Type A research, studies have also addressed the component parts to try and establish whether there is a key component.

Hostility itself has shown to be made up of emotional, cognitive and behavioural components:

- the central emotional component that is both experienced by the individual and manifested in aggressive or antagonistic actions or expressions is trait anger;
- cognitive components include having a cynical view of the world, a negative general attitude and negative expectations (cynicism, mistrust and denigration) about others' motives;
- and behaviourally, hostile individuals may appear overtly aggressive or angry.

In investigating the pathways through which hostility affected health status, trait anger, both inhibited anger (anger-in) and anger expression (anger-out) has consistently been associated with blood pressure and hypertension, and interventions to reduce hostility have been associated with reductions in blood pressure (e.g. Davidson et al., 2007). Furthermore studies have reported an increased CHD risk among participants with high anger expression (e.g. Williams et al., 2000), with anger inhibition or suppression more associated with hypertension risk (e.g. Vögele and Steptoe, 1993; Vögele et al., 1997). Importantly, a meta-analytic review of prospective studies – 25 studies with initially healthy samples, and 19 studies of those with existing CHD, (Chida and Steptoe, 2009) found hostility and anger increased the likelihood of an incident CHD event among healthy participants by 20 per cent, and significantly worsened the prognosis of those with CHD even when controlling for disease and treatment status. Effects were more pronounced for men than women. There also seem to be physiological correlates of hostility: for example, in addition to heightened stress reactivity, there is some evidence of an association with pro- and anti-inflammatory cytokines, discussed previously in relation to stress responses and potential associations with heart disease (e.g. among healthy male military personnel, Mommersteeg et al., 2008). There are also other psychosocial correlates with hostility, for example, hostile individuals may not benefit from social support (see later section) due to a cynical mistrust of others' motives, as suggested by Holt-Lunstadt and colleagues who found that the cardiovascular reactivity of hostile individuals did not benefit from discussing the experience of negative events with friends (Holt-Lunstadt et al., 2008).

One final thought on hostility. It has been suggested that risk 'characteristics' such as hostility may be created by certain social contexts that undermine an individual's ability to attain goals or financial security, and that hostility may be less of a trait than a defence mechanism or coping response (e.g. Taylor et al., 1997). Perhaps hostility is indirectly associated with disease by virtue of a relationship with social deprivation (e.g. Siegman et al., 2000) (see Chapter 2 ☛).

## Type C personality

The search for a disease-prone personality in relation to CHD, which led to identification and examination of Type A and hostility, stimulated research into whether or not there was a cancer-prone personality type. Two scientists that had separately been considering the existence of disease-prone personality types came together in 1980 in a collaboration that has become extremely controversial (e.g. Eysenck, 1985; Grossarth-Maticek et al., 1985). Over a decade their work, a lot of it based on a decades-worth of data collected separately in Hungary by Grossarth-Maticek before the start of the collaboration, identified four personality 'types'. These included: a 'cancer-prone personality', type 1, characterised by suppression of emotion (anti-emotionality) and inability to cope with interpersonal stress, leading to feelings of hopelessness, helplessness and finally depression; a CHD-prone personality, type 2, characterised by strong reactions of frustration, anger, hostility and emotional arousal (similar to TAB described above); and a 'healthy autonomous' and a 'mixed type. Following a large-scale community survey in Yugoslavia, Grossarth-Maticek reported evidence that type 1 increased individual risk of cancer by 120 times and type 2 increased CHD risk 27 times. These figures suggest that phenomenal amounts of risk can be conferred on personality variables, for example greater risk than that elicited even by smoking. These and other claims about how to intervene and reduce this risk (e.g. Grossarth-Maticek, and Eysenck, 1991) inevitably led to much scrutiny of their study design, methods and statistical analysis by scientists worldwide. Significant concerns on the grounds of inappropriate analyses, insufficient and inconsistent methodological detail, and a general inability of others to replicate their findings in either CHD studies or cancer studies (e.g. Amelang and Schmidt-Rathjens, 1996; Amelang et al., 2004), have led to calls for this work to be questioned, or even retracted (see Pelosi, 2019 for a detailed account including references to all the original articles and the refutational studies).

In another programme of work, involving a 15-year follow-up of women with breast cancer, Temoshok (e.g. Temoshok and Dreher, 1993) reported a robust finding of an association between passive and helpless coping style and poor disease prognosis. Their typology described a **Type C personality** with the following characteristics:

- compliant, passive and appeasing;
- stoic and likely to inhibit or repress negative emotions, particularly anger;
- unassertive and self-sacrificing/other focussed.

However, reviews of the role of Type C characteristics (and in fact any psychosocial factor) and cancer onset have found limited and weak effects (e.g. Garssen, 2004; Stürmer et al., 2006).

Other research has examined personality as a factor that influences the appraisal of, and response to, cancer and whether or not this can indirectly predict disease outcomes of recurrence or survival. Generally, support for the predictiveness of characteristics of Type C is again limited (Garssen, 2004; Stephen et al., 2007). There is mixed evidence of survival benefits of aspects of personality best described as 'coping styles', for example of 'fighting spirit' (see 'What is adaptive coping?' above), and of helplessness–hopelessness.

## Type D personality

Another construct has been examined in relation to CHD risk and that is a **Type D personality**, best described as a 'distressed' personality, with individuals scoring highly on negative affectivity (NA) and social inhibition (SI, defined as 'the avoidance of potential dangers involved in social inter-action such as disapproval or non-reward by others' (see, Kupper and Denollet, 2018; Denollet, 1998). Type D individuals experience negative emotions but inhibit them while also avoiding social contact: a combination of processes which appear to increase risk of poor cardiovascular disease prognosis and outcomes, including mortality after a heart attack or other **cardiac event**,) even when controlling for other biomedical risk factors, or for concurrent symptoms of stress. The effect has been found in both women and men who had pre-existing heart disease. A meta-analysis of twelve studies (Grande, Romppel and Barth, 2012), for example, found that combining data from all studies showed that Type D cardiac patients were nearly one and half times more likely to have a further cardiac event and/or die from CHD than those without this personality constellation after partialling out the effects of other risk factors. However, they also found that the size of this risk was highest in the early studies of Denollet, and reduced over time, with the three of the five most recent studies (including two with particularly large sample sizes) finding Type D individuals to be at no additional risk of disease progression or death.

In an attempt to identify physiological correlates of Type D personality so as to better understand the process by which Type D may achieve its reported effects, Habra et al. (2003) examined cardiovascular reactivity (blood pressure, heart rate, salivary cortisol levels) of students completing a mental arithmetic task while being harassed. Socially inhibited males showed heightened blood pressure reactivity; negative affectivity associated with dampened heart-rate changes during the task in males; and salivary cortisol levels positively associated with both Type D dimensions (but not in final, more stringent analyses). Unlike Denollet's studies, where NA and SI were only predictive jointly, Habra's findings suggested

### Type C personality

a cluster of personality characteristics manifested in stoic, passive and non-emotionally expressive coping responses; thought to be associated with an elevated cancer risk.

### Type D personality

a personality type characterised by high negative affectivity and social inhibition.

### cardiac event

generic term for a variety of end points of coronary heart disease, including a myocardial infarction, angina and cardiac arrest.

that NA and SI operated independently. By contrast, a well-controlled study by O'Riordan et al. (2020) found that Type D personality was associated with lower blood pressure reactivity to a mental arithmetic stressor given to undergraduate students and had no influence during a task in which they had to give a short speech. An alternative mechanism of effect may be quite different, and include psychoneuroimmunological responses, including that of increased pro-inflammatory cytokine activity, systemic inflammation, and poorer glycemic control (Jandackova et al., 2017) (see Chapter 11 ☛). Clearly, although there are fascinating results in relation to Type D personality the reasons for the apparently reducing effect size and the search for a consistent mode of influence need to be continued.

To conclude this section, generally speaking, there is reasonably good evidence that individual differences in aspects of personality influences the appraisals of events and the cognitive, behavioural and physiological responses made to them including the way in which people cope. While these influences may confer increased risk of some diseases, the influence of personality on disease outcomes such as survival is limited. We turn attention now to the more situational cognitions that have been associated with the stress experience.

## Stress and cognitions

### Perceived control

Early work on the construct of control considered it to be a personality trait, for example, locus of control (LoC), as derived from Rotter's social learning theory, was proposed as a generalised belief that would influence behaviour, because greater reinforcement (e.g. rewarding outcomes) was expected when responsibility for events was placed internally rather than externally (Rotter, 1966). Furthermore, internal locus of control beliefs would only predict behaviour in situations where the rewards/outcomes were valued. LoC referred to trait-like expectations that personal actions would be effective in controlling or mastering the environment, with individuals falling on the side of either internality or externality. An 'internal' individual would take responsibility for what happens to them: for example, they would attribute successes to their own efforts and their failures to their own laziness! An 'external' individual would be more likely to believe that outside forces or chance circumstances control their lives, and both success and failures would be likely to be attributed to luck or chance. These beliefs would influence a person's behaviour.

It is considered that internal individuals have more efficient cognitive systems and expend energy on obtaining information that will enable them to influence events of personal importance i.e. internally oriented individuals would engage in more problem-focused coping efforts when faced with personal or social stressors. Highlighting this, Henselmans et al. (2010) demonstrated in a longitudinal study of breast cancer patients that threat appraisals (primary appraisal) were greater, and secondary appraisals of coping ability were lower in women who reported low perceptions of control over events and situations in life prior to their diagnosis (using a measure of mastery, see later), and that this impacted on these women's subsequent distress. This shows how internal resources/beliefs and appraisals interact in a dynamic manner, and, furthermore, suggests a protective role for a general sense of personal control, or mastery (as assessed in this study).

Critical to the concept of locus of control is what we are trying to measure, i.e. 'control over what?' Various types of control have been described:

- *Behavioural:* the belief that one can perform behaviours likely to reduce the negative impact of a stressor, e.g. using controlled breathing techniques prior to and during a painful dental procedure.
- *Cognitive:* the belief that one has certain thought processes or strategies available that would reduce the negative impact of a stressor, e.g. distracting oneself from surgical pain by focusing on pleasant thoughts of a forthcoming holiday.
- *Decisional:* having the opportunity to choose between options, e.g. having a local anaesthetic prior to a tooth extraction (bearing in mind that the after-effects can last for hours!) or having the tooth removed without anaesthetic.
- *Informational:* having the opportunity to find out about the stressor; i.e. the what, why, when, where, likely outcomes, possibilities, etc. Information allows preparation (see Chapter 13 ☛).
- *Retrospective:* attributions of cause or control of an event made after it happens, i.e. searching for the meaning of an event can give some sense of order in

life: e.g. blaming a birth defect on a defective gene (internal) may be more adaptive than attributing blame externally, although this is not clear-cut.

Each of these types of control can reduce the stressfulness of an event by altering the appraisal a person makes of the stressor, by reducing emotional arousal or by influencing the coping responses adopted.

There is a large body of evidence relating locus of control to physical and psychological health, and much of it has employed a scale specific to health developed by Kenneth Wallston and colleagues (e.g. Wallston et al., 1978) – the multidimensional health locus of control scale. The MHLC, often used in conjunction with a measure of value for health, assesses the extent to which a person believes that they themselves, external factors or 'powerful others' (e.g. friends, health professionals) are responsible for their health and health outcomes. This measure therefore has three subscales and includes items such as:

- 'I am in control of my health' – internal;
- 'No matter what I do, if I am going to get sick I will get sick' – external;
- 'Regarding my health, I can only do what my doctor tells me to do' – powerful others.

Scores on these subscales have been found to be associated with a range of coping, emotional and behavioural outcomes (including health behaviour itself). For example, among two longitudinal studies of patients with lower back pain, internal HLC was associated with reduced physical disability at follow-up, and patients with stronger internal control beliefs gained more from their treatment and exercised more often (distress was associated with poorer exercise behaviour) (Härkäpää et al., 1991; Fisher and Johnston, 1998). Using an HLC measure specific to recovery from disability (the recovery locus of control scale; Partridge and Johnston, 1989), Johnston et al. (1999) also found that perceptions of internal control predicted better recovery from disability (measured in terms of the ability to perform a range of activities such as walking, dressing and toileting) six months after an acute stroke, although this was not achieved by means of an influence on exercise behaviours, as reported by the Finnish study (Härkäpää et al., 1991). Importantly, Johnston and colleagues reassessed their stroke survivors after three years to examine whether the beneficial effects of perceived control persisted long term, and confirmed that perceived control beliefs, as assessed at baseline (10–20 days post-stroke onset) were significantly predictive of long-term physical recovery, but not emotional recovery in terms of reduced distress (Johnston et al., 2004; Morrison et al., 2005). The importance of this type of finding is that, unlike neurological impairment or age (both predictors of outcome following stroke), control beliefs can be modified with simple (e.g. Fisher and Johnston, 1996a) or more intensive (e.g. Johnston et al., 2007) intervention.

Locus of control may itself predict other mediators of health outcomes, such as adherence to medication. Bąk-Sosnowsk, Wyszomirska and Daniel-Sielańczyk (2021), for example, found the powerful others dimension to be particularly predictive of adherence to rheumatoid arthritis medication (with internal locus of control also influential to a lesser extent). While LoC may also be related to the emotional outcomes of illnesses such as cancer (e.g. Lima, Morey-Tatay and Irigaray, 2021), few studies have found perceived control to be predictive of disease course. Furthermore, there is evidence that encouraging patients or research participants to increase internal control may not always be popular (e.g. Joice et al., 2010) nor adaptive, given that unrealistic perceptions of control could potentially lead to unrealistic optimism. However, the direction of causality is unclear here. Do optimists perceive control, or does perceiving control make you optimistic – only prospective studies can explore this (see Klein and Helweg-Larsen, 2002 for a meta-analytic review). Furthermore, maintaining beliefs in internal control in situations where such beliefs are unrealistic (e.g. severe and permanent disability following traumatic brain injury) may lead to problem-focused coping efforts that fail to achieve desired goals. This perceived failure may contribute to feelings of depression and helplessness, whereas accepting the reality of having no control could encourage more adaptive emotion-focused coping responses (Thompson et al., 1993; Folkman, 1984). Even in generally uncontrollable circumstances, revising one's goals for new, more realistic or attainable goals, such as believing in control over one's day-to-day symptoms rather than over one's disease as a whole, can maintain a sense of hope, reduce distress and benefit adjustment and reduced distress (e.g. Folkman, 2010; Montpetit and Bergeman, 2007; Stanton et al., 2007). Indeed, the core of Folkman's 'coping effectiveness training' approach aims to help participants identify the degree of control that can be given to any situation and to adopt the optimal coping strategy (emotion or problem-focused) to each situation (see for example, the work of Bose et al. (2016) in patients with chronic heart failure).

In a study of cancer caregivers, however, Fitzell and Pakenham (2010) found that perceived control over care-giving demands was not a significant predictor of any outcome, positive or negative. They investigated caregiver appraisals of demand (stress, challenge) and resources (personal control, social support) in relation to both positive, and negative, caregiver adjustment. While perceived control was not predictive in the final regression analyses, perceived stress (assessed as a single item) was a significant predictor of all outcomes in the expected direction; a more robust five-item measure of perceived challenge was predictive only of life satisfaction; and the 'resource' variable of satisfaction with social support also added significantly to the prediction of all outcomes. The authors suggest the lack of prediction of control beliefs (and also in fact of most of the coping subscales) may be due to using items which referred to control over caregiving challenges generally, rather than specific demands/caregiving tasks. This important issue of whether to assess constructs generically or specifically is one which we address at various points throughout this text. Illustrating this point, it was perceived behavioural control beliefs rather than more generic internal locus of control beliefs that were predictive of recovery of individual walking behaviours during the rehabilitation of stroke patients (Bonetti and Johnston, 2010).

Self-efficacy and perceived locus of control are the two main control concepts used in health psychology, and they could be considered as spanning different phases of the coping process: for example, locus of control is an appraisal of the extent to which an individual believes they can control outcomes, whereas self-efficacy addresses appraisal of the resources and skills an individual believes they can use in order to achieve desired outcomes. For example, across five different national samples, academic demands were more likely to be appraised as challenges than threats where self-efficacy was high (Luszczynska et al., 2005). Self-efficacy is typically correlated with the more specific construct of perceived behavioural control however their distinct contribution has been demonstrated with regards to health behaviour, for example healthy eating and physical activity (Parkinson, David and Rundle-Thiele, 2017) (and see also Chapter 5 ☛), and in relation to rehabilitation outcomes (Magklara, Burton and Morrison, 2014; Magklara and Morrison, 2015).

Another control-related construct is that of personal mastery (e.g. 'I can do just about anything I really set my mind to'). In a study examining mastery and another control-related construct perceptions of constraints in one's life (e.g. 'Other people determine most of what I can and cannot do') in a large sample of adults aged 25–75 years, personal mastery beliefs were lower and constraints higher among those with lower incomes (used as an index of social class). However, when lowest-income participants reported a high sense of control, their health and wellbeing became comparable with the higher-income groups (Lachmann and Weaver, 1998). This finding suggests that such beliefs can moderate the effect of low income on both physical (self-rated health, functional limitations) and psychological (life satisfaction, depressed mood) outcomes. Providing further evidence about how such beliefs may be beneficial, a five-year follow-up study of 2,471 Norwegian adults aged 40–79 years found high mastery beliefs be a significant predictor of youthful self-perceived age, with particular effects in those aged 60–69 years, rather than 40–49 or 70–79 (Bergland et al., 2013). Thus, rather than demonstrating a linear relationship with age, mastery seems to have particular effects, at least with regards to subjective or self-perceived age, in late middle age – when perhaps ageing begins to become a concern with regards to changes in physical or mental health.

## WHAT DO YOU THINK?

While findings such as those described above make general conclusions, there are obviously individuals who differ from the mean (in other words, some people of low socio-economic status (SES) will report high mastery, and some of high SES will report low mastery). However, thinking of the overall picture, stop and ask yourself why many people of a lower SES have a lower sense of control and greater perceptions of constraints in their lives than people of higher SES. Do you think they are right in having such views, i.e. might such beliefs be adaptive in certain circumstances? Refer back to Chapter 2 ☛ when thinking about these issues.

Finally, also related to control beliefs are **causal attributions**. In a review of 64 datasets exploring associations between attributions of cause in a wide range of conditions (including arthritis, cancer, heart disease, burns, AIDS, infertility, stroke and pregnancy loss) and adjustment (Hall and Marteau, 2003), contrary to expectations, 80 per cent of studies reported no association between internal (behavioural self-blame) attributions or external (other-blame) attributions and adjustment. In fact, no particular attribution was strongly associated with achieving a better outcome. Characterological self-blame (e.g. 'It is something in my nature that I can't change that caused me to become ill') was, however, most often associated with poorer outcomes, which fits with previous reports of associations between this type of self-blame and depression.

## Hope

Snyder and colleagues (1991a) introduced hope and its measurement to the study of cognitive–motivational processes involved in explaining human behaviour. Relevant to the study of stress and coping, hope was defined as 'a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy) and (b) pathways (planning to meet goals)' (Snyder et al., 1991b: 287). For Snyder, hope was fundamentally the person's belief that they can set, plan, and attain goals – hope emphasises goal-directed thinking and was believed to have both trait and state-like aspects. There is some conceptual overlap between the hope construct and other constructs, such as dispositional optimism and self-efficacy, both of which have also been associated with persistence in the face of goal challenges and positive physical and emotional wellbeing. Snyder et al. (2006) acknowledge that all three constructs focus on individual 'resources', but explained that hope is about the motivation (agency) and route (pathway) to achieving goals (outcomes), whereas optimism reflects a generalised positive outcome expectancy that is not founded solely on agency and pathway thinking, and self-efficacy is less a generalised belief than a situational and goal-specific belief that depends on various contingencies (i.e. I can do 'a' even if the situation is 'b'). (Some might question this, given that self-efficacy theories do also propose a more generalised construct.) Snyder further supported his argument by describing how a hope-based intervention would differ from an optimism- or a self-efficacy-based intervention, although the differences have not been fully tested. However, in their book, Snyder's colleagues (Lopez et al., 2014) suggest that together 'self efficacy, optimism and hope provide the momentum needed to pursue a good life' (p. 210), suggesting perhaps that interventions may be less concerned with their separation.

**causal attribution**

where a person attributes the cause of an event, feeling or action to themselves, to others, to chance or to some other causal agent.

Folkman (2010) described how 'Hope, like stress, is appraisal based, it waxes and wanes, is contextual, and is complex' (p. 902). For Folkman, hope is about more than goals; it is motivational but it is also in a bidirectional and active relationship with coping and is about emotion and finding meaning (Folkman and Moskowitz, 2000, and see also Chapter 14 ☛ for a discussion of finding meaning in an illness context). For example, when faced with a life-changing scenario, such as redundancy or illness, people may revise their goals in order to find one which falls more easily within their control which they can then imbue with hope. Hope in some contexts can have faith-like or existential qualities, for example, when coping with an uncertain future or a changing reality following diagnosis with a terminal illness (e.g. hope to find peace). Whether closely tied to goals, or more broadly defined, the construct of hope is hard to capture empirically. However, there remains a need for empirical studies to establish whether the measurable aspects of hope adds any 'unique' explanation in terms of mediating any effects of stress upon health outcomes, compared to that offered by assessment of other personal 'resource' variables such as those described in this section.

The constructs reviewed in this section are often referred to within a field of study known as 'positive psychology', i.e. where a person's strengths, resources and abilities are focused on and harnessed rather than their pathology, limitations or negative cognitions and emotions (see 'In the spotlight'). In the subsequent section, however, we return to addressing the more negative emotions found to be associated with stress responses and outcomes.

## IN THE SPOTLIGHT

### Coping with COVID-19: taking a positive approach to developing resilience

The stress associated with the SARS-Cov-2 virus (COVID-19) pandemic is an unusual form of stress inasmuch as it's cause is relatively unique and also the psychosocial challenges it results in – quite apart from any physical challenges being infected may bring – are also unusual. Coping with a crisis can result in a single, effective response, sometimes called a 'surge capacity' or response (Enns, 2021). This powerful response to stress is time-limited and quickly exhausted, but in fact coping with COVID-19 has presented a very different challenge. Stress in this context, even for those who have not been infected with the virus, has come in repeated waves, with the overall experience lasting months or even years. While there may be repeated peaks (high infection rates, high death rate, strict social measures), the troughs (in case and death numbers) are also pretty stressful as we wait to see whether behavioural measures are effective. How do we cope with long-term grinding stress? According to Enns, we need to build active resilience. She identified three sets of coping strategies through which we can achieve this:

1. *Chose a practical and realistic habit that will increase wellbeing*. The key here is to keep these habits small and meaningful, thus it could be anything from walking the dog to drinking more water. Changes may not be immediately obvious, but the regularity of these routines can help build patterns that increase stamina.
2. *Make one positive connection each day,*( involving a positive expression of gratitude, appreciation or humour), whether live, online or message/email. According to Enns, the time we have on our own or with limited positive social interactions can lead us to focus on our worries and concerns because we lack the interactions that could interrupt this process or provide more positive thoughts. She claims this daily connection will enhance wellbeing and resilience.
3. *Pause and really focus on now*. Anxiety and stress pull our attention to the future, our past, and worries of 'What if ... ?!' One key means of managing this involves taking regular times in the day to become fully immersed in the immediate present— to feel and smell the food you are cooking, or the damp autumn air in the morning, or to feel the rhythm of walking (your posture, the flow of air, the feel of the ground under your feet, etc). Here, we have the basics of mindfulness considered more in Chapter 13 ☛, or as Seligman may call it, flow.

These positive coping responses to build resilience may sound simple, but they form part of what Martin Seligman, a leading researcher in depression and then positive psychology, called his PERMA model of happiness. According to Seligman (see **positivepsychology.com**), resilience is based on five personal attributes:

- **P**ositive emotions including hope, joy, love and compassion.
- **E**ngagement in the present – the experience of flow
- Positive **R**elationships
- **M**eaning: that is, feeling of value and worth - feeling part of something that is wider than the self.
- **A**ccomplishments: feelings of achieving goals and a sense of working towards meaningful achievements and competence through endeavour and perseverance.

This may be further developed through optimism, nutrition, and exercise. The modern movement towards positive psychology embraces these approaches and can not just prevent unhappiness (the previous goal of most psychological interventions),but instil happiness.

# Stress and emotions

## Depression and anxiety

In Chapter 11 ☛ we described the evidence for or against the role played by stress in the onset of a range of illnesses, including cancer, coronary heart disease (CHD), bowel disease, HIV/AIDS, and within many of these studies the role of the negative emotions of distress, anxiety and depression were also examined. As early examples, the Framingham Heart Study found that depression, as well as anxiety, predicted 20-year incidence of hypertension even controlling for age, smoking and obesity (Markovitz et al., 1993), and, in relation to cancer, a major study showed that recurrent major depression among an elderly sample predicted a higher incidence of breast cancer (Penninx et al., 1998). More recently, a review of 25 studies found a 15 per cent increased risk of cancer overall, a 20 per cent increased risk of liver cancer and a 33 per cent increased risk of lung cancer in those with depression, but no relationship with breast, prostate or colorectal cancer (Jia et al., 2017).

The role of depression in increasing the incidence/likelihood of disease onset is controversial however and depends on many factors including study methods, samples and the disease concerned. Depression, and to a lesser extent anxiety, appear to be more implicated in the progress or outcomes of disease, as illustrated for example in Mittermaier et al.'s (2014) study whereby depression was a significant predictor of relapse in those with Inflammatory Bowel Disease, or Farinpour et al.'s (2003) 13-year follow-up of over 1,000 persons with HIV where depression was a significant predictor of disease progression and survival. As with stress-illness links (Chapter 11 ☛), much of the work in relation to distress-illness has focussed on CHD and cancer as we detail briefly below.

### Emotions and coronary heart disease

In relation to CHD, several reviews and meta-analyses have reported significant association between depression and CHD outcomes (heart attack, angina, cardiac death, as well as global CHD). For example, a large UK study (Surtees et al., 2008) found that of almost 20,000 CHD-free participant followed up on average for 8.5 years, that those diagnosed as having major depression were 2.7 times more likely to die from ischemic heart disease than those without depression, even when controlling for other known risk factors. Khan et al.'s (2020) systematic review of 17 longitudinal studies of predictors of the severity of atherosclerosis in people with no evident heart disease (see Chapter ☛) found 13 studies found an association with depression while four did not. Not surprisingly, the strongest findings were for people with recurrent depression and in younger individuals (e.g. those between 40 and 50 years) prior to the clinical consequences of this atheroma. These effects were generally found after controlling for other confounding factors. However, there was also synergy between depression and risk factors known to be higher among depressed individuals, for example smoking behaviour had a synergistic effect with long-term depression on risk for significant levels of atheroma (Carroll et al., 2017).

Zhang et al.'s (2019) meta-analysis of the impact of depression following a minor cardiac procedure (PCA) consequent to symptom onset found, from eight studies with over 3,000 patients, a 50 per cent increased risk of further adverse cardiac events if participants were depressed either immediately before the procedure or following it. In a wider review, Meijer et al. (2013) identified 16 studies involving over 10,000 post-MI patients and found a 19 per cent increase in risk of further cardiovascular events including potential confounding factors for every standard deviation increase in depression score and a 13 per cent increase after partialling confound out. Accordingly, there does appear a modest but significant increased risk of further cardiac events in post-MI depressed individuals.

### Emotions and cancer

The evidence of a role of depression on CHD onset is relatively consistent when compared to the evidence of emotions associated with increased cancer risk. For example, the large-scale longitudinal Alameda County study found no relationship (Kaplan and Reynolds, 1988). In the 1990s, two longitudinal studies of healthy, but older, samples followed over six years found inconsistent results, one finding an association between chronic depression and cancer incidence (Penninx et al., 1998), the other, finding no relationship (Whooley and Browner, 1998). It is worth noting of course that findings revealed among older individuals may not hold for middle-aged or younger samples. More recent studies do point more consistently to the role of having a history of depression in an increased cancer risk, as seen for example in two impressive prospective studies, firstly a 19-year study carried out with 601,775 adult Koreans (Chang et al., 2015) or a

24-year follow-up of an American sample where a history of depression significantly increased the risk of breast or prostate cancer – but not cancers of the skin, colon or lung (Gross, Gallo and Eaton, 2010). Curiously, in the Korean study, the association between depression was positive for men (prostate cancer) but inversely associated for women (cervical cancer), suggesting possibly different psychobehavioural or biological pathways.

Overall however the evidence appears to be, as with CHD, more consistently and strongly in support of depression influencing outcomes rather than aetiology (Petticrew et al., 2002). In a meta-analysis of over 282,000, patients in 17 studies diagnosed and successfully treated for breast cancer, for example, Wang et al. (2020) found depression was related to a 24 per cent increase in risk for breast cancer recurrence, and a 29 per cent additional risk for cancer-related mortality. By contrast, anxiety achieved similar levels of risk for breast cancer recurrence but was not associated with cancer mortality. Overall, key predictors of mortality were being under the age of sixty, female, and both depression and anxiety. Depression as an outcome of illness is addressed in Chapter 14 ☛.

## How can negative emotions affect health outcome?

When considering pathways by which depression or anxiety may affect health outcomes, there are, as with personality, various possible routes (see also ‘Research focus’).

### Influencing appraisals and coping responses

Firstly, negative mood states have been shown to influence the appraisals that individuals make when facing stressful events (appraisals of threat, as opposed to appraisals of challenge), thus influencing the coping actions a person engages in. For example, stress and distress may be maintained in those with the stable coping style/trait known as rumination, whereby a person will repeatedly rethink past events and worry about future ones (e.g. Davey and Wells, 2006; Wells, 2000). Rumination has been related to many ‘negative’ states including anxiety and depression, and has been shown to exacerbate negative future thinking and contribute to poorer problem-solving and is thought to be ‘stress-reactive’ (Robinson and Alloy, 2003). Although consistently associated with negative emotions, cognitive models of emotional distress in chronic physical illness rarely include rumination (Soo et al., 2009). It is likely that different aspects of rumination exist which have different effects: for example, a deliberate reflective rumination reappraises the situation to seek benefits and may be associated with post-traumatic growth, whereas life purpose rumination which revisits past events and losses and ponders one’s purpose in life, and a more perseverative intrusive rumination which is when unwanted thoughts of the negative experience regularly intrude into consciousness, are associated with negative emotions and coping responses (Brosschot et al., 2005; 2006). Rumination is, however, amenable to intervention (e.g. Segal et al., 2002), using, for example, mindfulness-based interventions (e.g. Foley et al., 2010; Gu et al., 2015) or therapy aimed at metacognitions (beliefs about beliefs) maintaining worry (e.g. Haseth et al., 2019) (and see Chapter 13 ☛). With regards to this latter point, a number of studies have relatively recently examined the association of meta-cognitions with depression and anxiety. For example, in medical populations, worry has been associated with positive beliefs about the benefits of worry, cognitive confidence, and cognitive self-consciousness. By contrast, and more impacting on negative mood, are beliefs that worry is uncontrollable and potentially dangerous (see Capobianco et al., 2020).

### Influencing behaviour

The second route in considering pathways by which depression may affect health outcomes is also indirect, i.e. via a person’s behaviour. Depression is seen to reduce the likelihood of healthy behaviour or cessation of unhealthy behaviour. For example, people with depression are less likely than non-depressed individuals to adhere to therapeutic interventions or treatments such as exercise or medication (e.g. DiMatteo et al., 2000; Wing et al., 2002) or attend cardiac rehabilitation classes (Lane et al., 2001). Conversely, others have demonstrated that positive affect in contrast may be necessary for maintence of health behaviour change (e.g. van Capellen et al., 2018, see Chapter 5 ☛). Non-adherent behaviour can of course expose individuals to a range of adverse health outcomes, such as future illness, poorer recovery from illness, or even mortality.

In addition, depression may also interfere with a person’s ability or willingness to seek, or benefit from, social support and supportive interactions (see later section).

### Influencing physiology

Thirdly, there may be physiological pathways through which depression exerts its effects. Pointing to this, individuals with elevated depressive symptoms but without a history of coronary disease were twice as likely as their non-depressed counterparts to have **carotid plaques** (a significant risk factor for CHD), and this association also controlled for baseline risk factors (Haas et al., 2005), suggesting that this association was not solely attributable to behaviours such as smoking. A link has also been made between depression and increased pro-inflammatory cytokines in older people with cancer (Spolentini et al., 2008), suggesting a further possible mechanism of effect. More immediately, the serotonergic dysregulation associated with depression is also responsible for making platelets in the blood more 'sticky' and likely to clot; proving an immediate increase in risk for MI (see Izzi et al., 2020).

### Other considerations in the negative emotions-illness relationship

The timing of depression may be important as demonstrated in the findings of Leung et al. (2012)'s meta-analysis of risk for evident CHD. They compared the risk associated with depression at varying times before the identified cardiac event and notably, depression at the time of the event appeared critical to the occurrence of the cardiac event, whereas a history of depression alone was not associated with disease onset. Furthermore, a combined history of depression and being in a current episode of depression conferred the highest risk (people in this category were more than 2x as likely to experience a cardiac event than those who had never been depressed).

Depressed mood may also reflect or coexist with other underlying factors, and it is likely that, for some individuals, psychosocial risk factors cluster together: for example, stress plus hostility plus depression plus social isolation would confer compounded risk. A further important issue was noted by Irvine et al. (1999) following a study of a cohort of 671 patients over a two-year period following MI. She noted that there is considerable overlap between the symptoms of fatigue and depression and questioned whether the findings often attributed to depression may be in fact attributable to a state of physical fatigue or exhaustion. However, while their analyses showed that fatigue and depression were correlated over the two-year period, both variables were independently associated with risk for sudden cardiac death (although the strength of the relationship between depression and death did in fact reduce on adding fatigue to the regression analysis).

Finally, it is should be noted that anxiety and depression themselves are interrelated (Suls and Bunde, 2005) and, although depression is perhaps more commonly found to be associated with CHD, and in fact all-cause mortality, anxiety also plays a role (Grossardt et al., 2009).

carotid plaque

a plaque is a thick waxy coating which forms on blood vessel walls and restricts blood flow, in this instance in the carotid artery.

**RESEARCH FOCUS**

### ARE MORE POSITIVE EMOTIONAL CONSTRUCTS NEEDED IN STUDYING STRESS AND HEALTH OUTCOMES?

Schache, K., Consedine, N., Hofman, P., and Serlachius, A. (2019). Gratitude- more than just a platitude? The science behind gratitude and health. *British Journal of Health Psychology*, 24: 1–9

Unusually for a Research Focus the paper selected here is an editorial, not an empirical article. It is selected as an example of how a commentary paper such as this can help develop a field. By reviewing current evidence, highlighting gaps, and then making an explicit call for further empirical study, theories can be developed and tested, confirmed or rejected. Positive psychology has become 'popular' yet there is a limited evidence base around some of the constructs it highlights in terms of whether they have any role to play in physical health outcomes, or whether their realm of influence is more subjective.

Here the focus is on 'gratitude, a construct conceptualised both as a trait i.e. individual differences in the average occurrence of feeling grateful in day-to-day life, and as a state i.e. where gratitude is felt in response to a particular experience (Emmons, 2004). The Editorial notes consistently found associations between these constructs and psychological wellbeing among

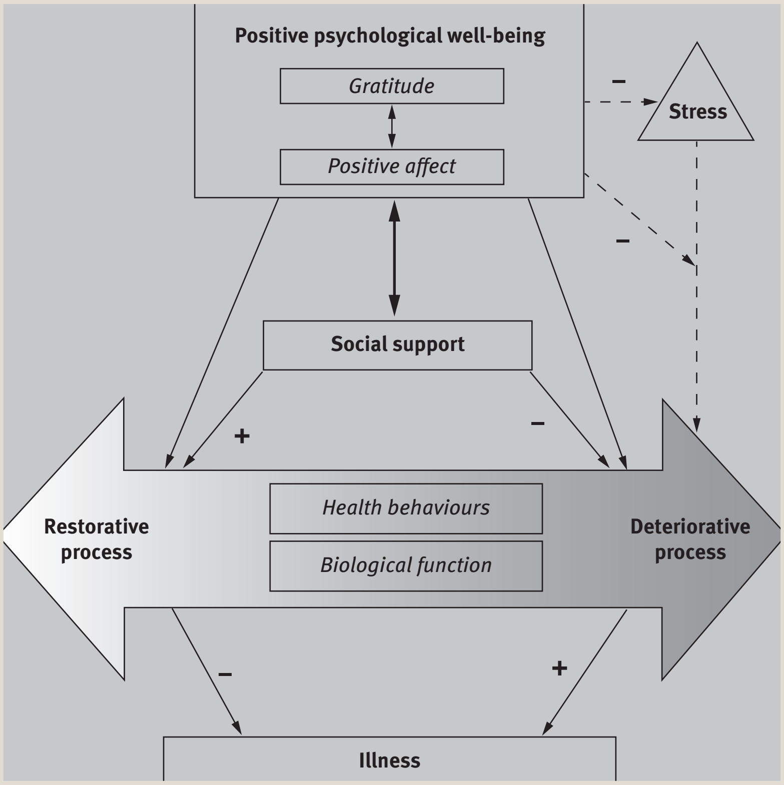


**Figure 12.4** Adapted model of psychological wellbeing

*Source*: Adapted from Boehm et al., 2012.

healthy adults, and points to observational evidence from patient populations of an association between gratitude and improved health behaviours and adherence. However observational evidence has had mixed support from interventional studies involving gratitude journals, gratitude contemplations, or gratitude as part of wider positive psychology interventions.

Given that some do find associations, it is important to examine possible mechanisms of effect. From healthy population studies gratitude appears to benefit mood and even blood pressure, although in comparing with broader positive psychology interventions it is unclear if gratitude has distinct effects. Fewer intervention studies with patient populations have been conducted (fewer than 10 in 15 years!), and those that exist provide limited evidence of effectivenesss overall (e.g. Dickens, 2017). Inconsistent effects are reported on a range of outcomes, with those reporting positive effects more consistently doing so in relation to affective or psychological outcomes (subjective) as opposed to objective outcomes e.g. viral load, functional status, although these do exist in some cases.

What Schache and colleagues propose is that a theory is needed upon which a model of gratitude can be built and tested. They propose adapting Fredrickson's 'broaden and build theory', described earlier in this chapter (and see Figure 12.2) , whereby positive emotions broaden a person's responses and help develop coping resources. They add consideration of mechanisms arising from health behaviours, biological functioning and physiological processes in order to propose causal pathways by which the 'broaden and build model' may achieve its effects. They recommend this because these pathways can be tested e.g. does gratitude benefit health outcomes because it changes a person's health behaviours and/or biological or physiological responses to stress?

As yet Schache's proposals have not been fully tested, and they point to another model and how it has been proposed to affect physical health, particularly cardiovascular health- that of Boehm and Kubzansky's (2012) model of positive psychological wellbeing. In this model the pathway between wellbeing and reduced cardiovascular disease risk operates via wellbeing's positive effects on restorative health behaviours and biological function, and reduction of deteriorative/risk processes. By adding 'gratitude' as a component of wellbeing, and incorporating social support as another influence on the pathway to better health, see below, Schache's adapted model is ready to be used (**see Figure 12.4**). The proposed model will help to structure gratitude research and enable testing it out for direct and indirect effects. They call for carefully designed experimental studies, ideally conducted with clinical populations, that test out the various constructs and the proposed pathways. Interested anyone?

### Post-traumatic stress disorder

Often considered as an outcome of trauma, including for example acute onset illness or invasive treatments (see Chapter 14 ☛) the symptoms of PTSD themselves can increase the risk of an individual experiencing further negative events. Typical symptoms of PTSD include flashback memories of a trauma event in which the individual re-experiences the trauma, including the emotions experienced at the time, which usually involve high levels of fear. A second symptom is rumination, and a third is known as hypervigilance. The threat response areas of the brain and the sympathetic nervous system (see Chapter 11 ☛) are on constant alert and the individual is over-responsive to daily hassles, frequently responding with anger or anxiety that they find difficult to explain. As a consequence of this hyper-arousal the individual is likely to be at further risk for conditions we know are affected by chronic stress. Sumner et al. (2015), for example, found in their cohort of nurses that those who had been exposed to trauma and experienced high levels of PTSD symptoms were 60 per cent more likely to have a cardiac incident than not being exposed to trauma. This relationship remained after accounting for health behaviours or medical risk factors. PTSD has also been linked to precursors of heart disease including hypertension (Mendlowicz et al., 2021) and in a meta-analytic review was found to double the risk of recurrence among acute coronary syndrome patients (Edmonson et al., 2012). Finally, a systematic review of 150 studies of cardiac-disease-induced PTSD found an average prevalence of PTSD of 12 per cent (range 0–38 per cent across studies) with pre-morbid distress being a key risk factor (Vilchinsky et al., 2017) suggesting that some individuals may be more vulnerable to PTSD than others because of their psychological comorbidity (Ayers et al., 2009).

## Emotional disclosure

One possible moderator of coping is that of emotional disclosure – the opposite of emotional suppression, or repressive coping, commonly found to be detrimental to health (see earlier 'Type C personality' section). A leading figure in this area is Pennebaker (e.g. Pennebaker et al., 1988; Pennebaker, 1993), who with various colleagues developed a paradigm whereby writing about one's feelings regarding a recent trauma (typically for 15 minutes, for several consecutive days) is shown to have long-term benefits in terms of reduced stress (Zakowski et al., 2004), immune functioning, including wound healing (Pennebaker et al., 1988; Petrie et al., 2004; Weinman et al., 2008) and healthcare use (Pennebaker and Beall, 1986). A large meta-analysis of 146 such studies supports the potential of this low-cost intervention (Frattaroli, 2006). In addition, the social context in which verbal emotional disclosure takes place can also affect emotional, cognitive and physiological adjustment. For example, in an experimental study where female participants exposed to a stressful factual video (of a gang-rape scene) were assigned to either a 'no-talk', 'talk-alone', 'talk to a supportive confederate' or 'talk to a challenging confederate' it was those who talked to a more challenging confederate (who promoted a more sanguine view of the stressor) who showed most gains (Lepore et al., 2003).

Disclosure of emotional experiences is not to be confused with work on **expressed emotion** (EE; can include

expressed emotion

the disclosure of emotional experiences as a means of reducing stress; often achieved by describing the experience in writing.

the venting of negative as well as positive emotion) which, although often studied using a similar writing paradigm, has been associated with poorer prognosis among psychiatric populations and is showing contradictory findings among the physically ill (see a meta-analysis by Panagopoulou et al., 2002). It is thought that venting negative emotion may maintain the emotion by virtue of increasing the attention paid to it; it can also interfere with the potential to receive social support (Semmer, 2006). Other authors suggest that EE assists in emotional self-regulation by allowing the person to develop greater mental control over the stressor and a coherent narrative of events in their head, which facilitates 'closure' and reduces distress (Niederhoffer and Pennebaker, 2005). While this may be the case for individuals, within couples venting negative emotion may have unwanted or different effects however, as reported, for example by Bakhshaie and colleagues (2020). They examined EE in discussions among couples where one had a diagnosis of a head and neck cancer and found that while patient expression of negative emotion did not affect spousal cognitive processing (hypothesised to reduce distress), where spousal partners expressed negative emotions (such as disdain or criticism) patients did exhibit poorer cognitive processing. As with previous authors (e.g. Davidson et al., 2000) it appears that the style of expression (e.g. antagonistic vs. constructive expression of anger) influences whether the outcome of expression is positive or not and thus Bakhshaie cautions against advocating emotional expression as a means of managing distress without first considering who is expressing emotion to who, and the valence or nature of the emotion expressed.

This leads us nicely onto consideration of an aspect beyond the individual that may moderate or influence a stress response- that of social support.

## Social support and stress

Several decades of research within psychology, sociology and epidemiology has evidenced that people who have strong (in both size and usage) networks of social support are healthier and live longer than the socially isolated (Cohen, 2004; Cacioppo and Patrick, 2008; Umberson et al., 2010). Having social ties, being in a social network and receiving social support is available to most people at some points in their lives, but is not experienced by all people at all times (see also Chapter 15 (☛). What do we mean by the term 'social support'?

### Definition, types and functions of social support

Social support can be actual (received support) or perceived. People with social support believe they are loved and cared for, esteemed and valued, and part of a social network of communication and mutual obligation, such as that often shared with family, friends or members of a social organisation. Sources of support can include anyone from partners, close family and friends, to colleagues, to health and social-care professionals and support groups.

Social support is generally considered in terms of two interacting components – its structure (i.e. type of support, size and density of networks) and the function(s) they serve (Uchino, 2006). The social network facilitates the provision of goods, services and mutual defence in times of need or danger (Cobb, 1976), however, people may vary in the extent to which they participate in these networks – how 'tied' they are to those within them, and what they offer the person. People also differ in how they perceive the quality of relationships within their social networks and how satisfied they are with the support they receive from them (Rokach, 2011).

A lack of integration with one's supportive resources is often referred to as social isolation, which is a recognised risk factor for poor wellbeing; however, a lack of satisfaction, or meaningful connection with one's relationships, no matter how many the person has, is more likely to be associated with, as Utz and colleagues describe (Utz et al., 2013) a 'state of mind' called loneliness. In studying social support, therefore, one must not only be aware of the interconnectedness of the common terms of 'social support', social networks' and 'social integration' (Gottlieb and Bergen, 2010), but furthermore, consider the individual's appraisals of their support, as this distinguishes *two qualitatively different experiences*, that of being alone, and that of feeling alone/lonely.

Table 12.3 presents examples of types of social support and their functions in terms of what the social support provider provides and in terms of what is received by the recipient. Some support may be global (i.e. from people generally) or specific to one event or support person. Five basic types have been described, although the most

**Table 12.3** Types and functions of social support

| | Provider | Recipient |
|---|---|---|
| Emotional support | Empathy<br>Caring<br>Concern | Reassurance<br>Sense of comfort and belongingness |
| Esteem support | Positive regard<br>Encouraging person<br>Positively comparing | Builds self-worth<br>Sense of competence<br>Being valued |
| Tangible/instrumental support | Direct assistance financial/practical aid | Reduces strain/worry |
| Informational support | Advice, suggestions feedback | Communication self-efficacy/self-worth |
| Network (or 'companionate', cf. Gottlieb and Bergen, 2010) support | Welcoming<br>Shared experiences | Sense of belonging<br>Affiliation |

common distinction is between instrumental, emotional and informational. Most studies do not attempt to record what the recipient actually 'gets' from the support but instead assume that it is all helpful. (Chapter 15 ☛ challenges this assumption when care-giver and care-receiver relationships are examined in terms of whether support given 'matches' what is needed or desired). Furthermore, some studies assess perceived support which is a person's belief that support is available to them, whereas others address actual received support, and there is evidence that this is an important distinction, particularly where there is a mismatch between what is expected and what is received. Perceived support is often more predictive of outcome than actual received support (Uchino, 2009; Uchino et al., 2012). In fact having to seek it out rather than receive what was anticipated spontaneously can have a negative impact (E. Lawrence et al., 2008).

Social support is considered within Lazarus's stress and coping framework as a resource variable that when perceived as being available will affect how individuals appraise and respond to, i.e. cope with, events. Individuals who perceive support levels as high are likely to appraise events as less stressful than individuals who do not perceive they have any support (i.e. social support acts as a 'buffer' against stress). Evidence of the association between social support and health outcomes is reviewed below, followed by consideration of some of the likely mechanisms of action. First, however, it is worth highlighting that social support may show different patterns in different people. For example, there is evidence that socio-economic and cultural factors shape the extent to which individuals can access social networks which facilitate support provision and receipt (Chaix et al., 2007; Parveen et al., 2011). A gender difference has also been reported whereby friends were found to benefit men's and women's wellbeing equally, but for men, family support had a stronger effect (Cable et al., 2013). In addition, although the size of one's social network has been generally found to reduce with age and become proportionally more composed of family than non-kin friendships, this does not inevitably mean the quality of support is less (Soulsby and Bennett, 2015).

## Social support and mortality

Many years have been spent trying to establish whether receiving social support is causally implicated in mortality. Early support was obtained from the Alameda County study (Berkman and Syme, 1979), showing almost a twofold increased risk of mortality for both men and women with fewest social ties, even when health status and self-reported health-risk behaviour were controlled for. Social isolation (low social support and social activity) was associated with heart disease mortality among middle-aged men followed up for ten years (Orth-Gomér et al., 1988), and in a 15-year follow-up of 2,603 adults (Vogt et al., 1992), social 'networks' (size, number of supportive domains, frequency of use) strongly predicted mortality from ischaemic heart disease, cancer and stroke. More recently, evidence from a meta-analysis of data from 148 studies involving more than 300,000 people by Holt-Lunstad et al. (2010) showed that people with adequate social relationships (size and function) had a 50 per cent lower mortality risk compared to those reporting poor social relationships (p. 14) and low social support, although variously defined in the reviewed studies, was related to a higher risk of premature mortality from all causes. In fact in a subsequent meta-analysis, living alone, social isolation and loneliness were associated with a significant and worrying 26–32 per cent increased risk of premature mortality (Holt-Lunstad et al., 2015).

## Social support and disease

Evidence of a relationship between life stress and health status has pointed to social support as a moderator (for a review, see Taylor, 2011). Among healthy samples, a large sample of French employees (Melchior et al., 2003), a lack of social support and dissatisfaction with social relationships predicted poor health status. In terms of being related to disease incidence, perceived functional support has been associated with cardiovascular disease incidence (Barth et al., 2010), and both higher structural and functional support reduced the risk of new diabetes among a large Hispanic/Latino sample, a family-oriented and collectivist population whose cultural norms stress the importance of family ties and strong familial support (Gallo et al., 2015).

Social support is also implicated in disease prognosis and outcomes, for example among individuals suffering from rheumatoid arthritis, a limited social network was predictive of disease activity three years later, even when coping behaviour was controlled for (Evers et al., 2003).

One measure of social support commonly used among older samples is the Duke Social Support Index (23-item version or an abbreviated 11-item version, e.g. Koenig et al., 1993) which assesses both satisfaction with support (e.g. ‘Does it seem that your family and friends (i.e. people who are important to you) understand you’?) and social interaction (e.g. ‘How many times did you talk to someone, friends, relatives or others on the phone in the past week (either they called you or you called them’?). Used in a large (12,000) nationally representative sample of Australian women aged 70–75 years (the Womens Health Australia cohort) (Powers et al., 2004), the association between social support and both physical and mental health was confirmed. In particular, the ‘satisfaction’ rather than the ‘interaction’ factor was significant, demonstrating the importance of quality over quantity. Within older adults where loss of social relationships is common, it may be important to balance a need for solitude with a need for contact with others. Social conflict within one’s reduced social network can be detrimental to emotional wellbeing (Rook et al., 2011; Rook, 2015).

## How does social support influence health status?

We all need support. There is ample evidence that social support effectively reduces distress during times of stress, and furthermore the lack of social support during times of need can itself be very stressful, particularly for people with high needs for social support but insufficient or altered opportunities to obtain it, e.g. the elderly, the recently widowed and other victims of sudden, severe or uncontrollable life events (e.g. Balaswamy et al., 2004; Stroebe et al., 2005, Utz et al., 2013). There is, however, more evidence for the benefit of social support in reducing stress and distress during illness than there is on actually preventing it occurring.

Two broad theories as to how social support might operate have been proposed (Cohen, 1988):

1. *Direct (main) effects hypothesis*: social support is beneficial regardless of the amount of stress people experience, and a lack of social support is detrimental to health even in the absence of stress. High levels of social support provide greater ‘ties’ to others and a greater sense of belonging and self-esteem than low levels, thus producing a positive outlook and healthier lifestyles. Alternatively, social support has a physiological route to health by virtue of either reduced blood pressure reactivity, thought to arise from positive stress appraisals and emotions, or possibly via enhanced endocrine or immune system functions, although there are less consistent findings in this area. (For a comprehensive review, see Uchino, 2006.)
2. *Buffering hypothesis*: social support comes into play in situations of high stress to protect the person against negative effects. Social support acts as a buffer by either (a) influencing the person’s cognitive appraisals of a situation so they perceive their resources as being greater to meet threat; or (b) modifying the person’s coping response to a stressor after it has been appraised as stressful (e.g. social support encourages positive thinking or behaviour) (Cohen and Wills, 1985; Badr et al., 2010).

### Evidence for direct effect of social support

In terms of direct effects, there is reasonably consistent evidence that social support facilitates healthy behaviours such as not smoking and adhering to medication, although, as discussed in Chapter 5 ☛, social influence can also be negative. It is likely that social support enables the individual, for example, by promoting their self-efficacy beliefs. For example, when stopping smoking, a supportive person, perhaps someone who has already quit smoking themselves, can provide assurances and enhance the other person's confidence and self-efficacy for change (Schwarzer and Knoll, 2007). Studies have also demonstrated beneficial effects of social support for psychosocial wellbeing among both healthy and ill populations. For example, marital support has been shown to benefit partner mental and physical wellbeing, although some studies show stronger effects for male partners than for females (Kiecolt-Glaser and Newton, 2001), possibly reflecting gender differences in ability to seek or provide needed support, and also in the response to it (see also Chapter 15 ☛). Here we consider more the direct effects of social support on physiological rather than behavioural processes.

Uchino (2006) reviewed the evidence regarding physiological pathways affected by social support, and highlights both reduced stress reactivity seen in typical measures of cardiovascular reactivity (see Chapter 11 ☛) and also some evidence of neuroendocrine and immune responses, the latter particularly important among older samples. However, this review primarily addresses experimentally manipulated support and we need to consider 'real-world' evidence also. Turner-Cobb et al. (2000) found that breast cancer patients who assessed social support as being present and helpful had lower morning cortisol levels than those who did not assess social support in this way, suggesting a physiological route by which social support may enact its benefits. As described in Chapter 8 ☛ and Chapter 11 ☛ cortisol has been implicated in immune down-regulation and is perhaps implicated in tumour growth. Cognitive-behavioural interventions that have provided breast cancer patients with group support have also reported reduced cortisol levels (e.g. Creuss et al., 2000). A review of social support and cardiovascular disease and cancer risk has also highlighted a role for the immune system and biochemical processes of inflammation, involving pro-inflammatory cytokines and interleukins (see also Chapter 11 ☛; Penwell and Larkin, 2010). While the evidence is not conclusive, such reviews certainly offer exciting insights into some of the potential mechanisms through which social support achieves its beneficial effects on health.

## ISSUES

### Is giving support to others good for your health?

Studies by Poulin and colleagues (e.g. Poulin and Holman, 2013; Poulin et al., 2013) have suggested a physiological route to wellbeing offered by being helpful to others. In a series of studies adults were assessed in relation to:

- stressful life events exposure;
- 'prosocial behaviour' whereby a person is involved in their communities e.g. giving blood donations, giving money or time to charity, being involved in a community action;
- group membership, e.g. of religious, community or social groups such as youth clubs;
- lifetime self-reported physical and mental health ailments (diagnosed)
- their oxytocin receptor genotype (OXTR).

The latter of these, OXTR, needs further explanation – this neurohormone when administered experimentally has been found to motivate parental caregiving behaviour in animal research (e.g. Lim and Young, 2006), and as referred to in Chapter 11 ☛ in humans in terms of the tend and befriend response to stress (Taylor et al., 2012) and has been shown to modulate HPA (hypothalamic–pituitary–adrenal) pathway activity as well as cardiovascular reactivity in response to stress.

Given findings that prosocial behaviour was associated with positive health outcomes, Poulin's studies sought to identify whether oxytocin was the mechanism behind these effects. They confirmed this hypothesis, finding that oxytocin mediated the negative effects of stressful life events on the onset of new health conditions experienced over a two-year period, in those with a specific type of oxytocin receptor genotype. This effect was further mediated by prosocial behaviour, suggesting that charitable behaviour may have boosted the compromised oxytocin release that characterises those with the genotype. Although this does not mean that acting in a charitable manner benefits everyone's health (only those with this specific genotype) and instead suggests perhaps that being charitable is underpinned by genetics (hence Poulin's research being described as the 'neurogenics of niceness'). Although fascinating, this line of research still needs extension and replication. Our discussion of social trust later in this chapter would however suggest that being charitable or volunteering does have the potential to benefit many of us, by developing social capital for the benefit of wellbeing.

**Photo 12.2** From an early age, social support is a powerful moderator of stress response

*Source*: Tanya Louise Robinson, Kirsten Fearn.

## Evidence for indirect or 'buffering' effect of social support

The effect of perceived and actual social support on the appraisal of stressful events has not perhaps been frequently studied, although there is some evidence that perceiving social support as being available contributes to more positive outcome expectancies and appraisals of control over the event. Also, the nature of support extended to participants in an experimental study where a negative event was simulated, was found to impact on event processing, attributions made, perceptions of self and future, and emotion reported (Marroquin et al., 2019).

Generally speaking, seeking social support is considered an active coping strategy, whether the support is sought for informational and practical reasons or with the goal of emotional support. This can be seen in in a study of the coping strategies of young people within two months of developing cancer, where Kyngaes et al. (2001) found that accessing social support was one of the most common coping strategies used. Different 'functions' of support were seen, i.e. they sought information about their disease and its treatment from health professionals, and emotional support from their families. Seeking information about one's condition or about what lies ahead in order that one can plan is considered a form of **proactive coping**, as opposed to reactive coping. Other skills that reflect proactive coping are goal setting,

proactive coping

the process of anticipating potential stressors and acting in advance either to prevent them or to minimise their impact.

organisation and mental stimulation (cf. Aspinwall and Taylor, 1997). In proactive coping, a person's efforts are aimed at goal management, with altered events or demands seen more as challenges than threats, and it appears that social support promotes proactive coping because resources from one's social network help shape one's choice of coping strategy. Greenglass and colleagues (2006) examined proactive coping among an elderly sample of community-residing older adults, in order to examine its direct or indirect effects on functional disability (FD). Functional ability or disability is predicted by factors described in this chapter, including personal resources of health status, age and social support, and by the manner in which the individual copes with stressful events. While the hypothesis that proactive coping would predict less FD was supported, the hypothesised direct association between social support and low FD was not supported, and an association (positive) between depression and FD was. Social support however enhanced the proactive coping efforts these elderly participants engaged in and, as such, can be described as mediating the effects of social support on functional disability. Proactive coping was associated in fact with both less depression and less functional disability. The measure used did, however, suggest some overlap with self-efficacy, for example, items such as 'I always find a way around obstacles, nothing really stops me' and so potential opportunities for intervention to enhance proactive coping might operate via self-efficacy training. Related to self-efficacy is the concept of personal control and perceptions of control have been shown, in a meta-analysis of 45 studies (Hagger and Orbell, 2003), to be associated with seeking social support, albeit to a more modest degree than expected. The limited associations shown may in part be explained byt the fact that social support was often assessed only by items contained within a coping measure, rather than by a specific measure of the structure and function of social support.

## Gender and cultural influences on seeking support

Gender is considered to be a robust predictor of the use of social support, with many empirical studies finding that females have a greater tendency both to seek and provide social support, and as a result tend to report larger social networks than males. Taylor (2006) suggests that female socialisation may generate a 'tend and befriend' response in times of stress, whereby nurturing loved ones or seeking and maintaining supportive networks are characteristic coping behaviours. Within spousal relationships, male partners tend to receive their support from female spouses, whereas female partners tend to receive support from female friends and relatives.

There are consistent findings that cultural differences exist in the norms of support-seeking behaviour and in the perceptions of available support, where Asian cultures, which have a collectivist rather than individualist orientation, tend not to seek or expect support (V. Lawrence et al., 2008; Kim et al., 2009). As Kim et al. state, 'people in the more collectivistic cultures may be relatively more cautious about bringing personal problems to the attention of others for the purpose of enlisting their help because they share the cultural assumption that individuals should not burden their social networks and that others share the same sense of social obligation' (p. 519). In contrast, Europeans, and Americans, use friends for support as much as, if not sometimes more than, family (Taylor et al., 2004; Chun et al., 2007; and see review by Parveen, 2011). Asian samples (including Chinese, Korean, Japanese), for example, carers of those with chronic or disabling illness (see Chapter 15 ☛) consistently report receiving significantly less social support than that reported by white American carers (e.g. Chun et al., 2007; McCabe et al., 2005; Katbamna et al., 2004). Interestingly, however, this difference may only be at a very broad level i.e. between Asian and non-Asian. The difference seems to lie in the 'seeking' of support, with Asian individuals exhibiting reluctance to disrupt relationships by talking of personal problems and seeking explicit support. Taylor et al. (2007) found that in Asian cultures the perception of having the 'implicit support' of others was more acceptable than explicitly seeking or receiving support, as it does not necessitate any disclosure of problems to others. Implicit support was both biologically (seen in reduced cortisol responses) and psychologically (seen in reduced stress scores) more beneficial to their Asian American participants, with the reverse actually being true for European Americans for whom explicit support is preferred and more beneficial. Differences are seen in other cultures also, for example, Lincoln et al. (2003), for example, found that Black Americans turned to family for support to a greater extent than did White Americans. A review of studies relating to cultural difference is found in Kim et al.’s (2009) paper, and strongly highlights the need for cultural norms to be taken into account when, for example, considering any intervention which aims to deliver explicit support.

Related to cultural norms of social support is an approach that considers the role of the wider community. Most social support research within health psychology has focussed on the benefit’s to the individuals’ wellbeing or health, whereas paying attention to **social capital** (Putnam, 2001) alongside personal wellbeing addresses ‘a more communal concept concerning reciprocity, networks and trust that develop between people’ (O’Brien et al., 2011: 72). O’Brien has shown in terms of studies of volunteering, that working cooperatively with others to achieve shared goals or to cope and deal with difficulties can build a person’s sense of social capital and subsequently benefit groups and communities beyond the individual. Social capital, often measured by assessments of social trust and social participation, can increase the resources individuals have, supporting them to ‘weather storms’ (Helliwell et al., 2016:16) and an absence of social trust is often associated with social inequality, which we also know is an important influence on stress, health and illness (see Chapter 2 ☛). Social capital that exists at a community and an individual level, offers supportive resources, opportunities for mutual exchange, participation and collaboration, and from this, a resilience to deal with stress. This has been seen, for example when faced with natural disasters, national economic collapse, unemployment, discrimination or other adversity (Aldrich, 2011; Helliwell, 2016) but also importantly, growth in social trust has been seen following a disaster, with community coming together with benefits for mutual wellbeing and happiness (Fleming et al., 2014; Uchida et al., 2014). While much of this research exists outside mainstream health psychology, it is increasingly recognised that we should be situating individual experience within it’s wider context, as we endeavour to do throughout this textbook. Indeed, constructs such as a sense of community, social trust and reciprocity are likely to benefit the psychological study of stress responses, with implications potentially for intervention (O’Brien et al., 2011; Abbott and Freeth, 2008).

**social capital**

social capital (often includes cultural and economic capital) is gained from the networks around people and communities that engender reciprocity, trust, participation and cooperation (Coleman, 1988; Putnam, 2001).

## Can social support be bad for you?

The type of social support provided may not always be received as supportive, or, more importantly, the help offered may not match the needs of a person (Rook et al., 2011, Rook, 2015). For example, instrumental support is helpful if aspects of the event are controllable, whereas emotional support may be more helpful when things are uncontrollable, e.g. after a death (e.g. Cutrona et al., 2007). Furthemore, an operant conditioning model of pain (Fordyce, 1976) suggested that over-responding to pain behaviours would be detrimental to a person’s adaptation. While some evidence supports this, for example, among chronic pain patients where solicitous support was positively associated with disability, other studies do not support this and point instead to solicitous care improving the alternative outcome of patient-carer relationships (e.g. Cano and Williams, 2010; McWilliams et al., 2017). In Chapter 15 ☛ we will describe a more systemic extension of Lazarus’s transactional stress-coping model which has been described in this and the previous chapter, where the interdependence between the support provider and the support receiver is considered more fully (e.g. Falconier et al., 2013).

Finally, there is a caveat in social support research typically addressed within health psychology. Given the subjectivity of the construct, studies have to rely on self-report which carries inherent biases, other than self-presentation bias. For example, individual difference variables, such as neuroticism, may influence an individual’s perceptions of the nature and level of social support they receive but also their satisfaction with it, and furthermore personality or emotional state might interfere with a person’s willingness to access social resources or the ability to gain from it (see discussion of hostility or depression). These confounding factors therefore need consideration in any social support enhancing interventions.

## SUMMARY

This chapter has shown that considerations of direct effects of stressful events on health and upon illness outcomes are overly simplistic. Many factors moderate these relationships. This chapter has described how factors attributed to a person's personal profile (age, gender, ethnicity), personality, beliefs, emotions (both positive and negative), and social support can affect stress responses in terms of appraisals of events, coping with events or in terms of physiological responses, which in turn influence health outcomes. Many such variables can be studied in terms of the direct relationships they have with stress and illness outcomes, or as variables that need to be controlled for when examining other predictors. For example, while one study might examine whether trait neuroticism predicts psychological distress following surgery, another study might control for neuroticism in examining the effects of a pre-surgical information sheet on patient distress following surgery. Whatever the research question, it has become increasingly clear that many variables influence our appraisals of events and how we cope with them, and that biological, psychological and sociocultural factors work together in the stress–health–illness experience. When developing interventions, described in the subsequent chapter, it is clear that the intervention target could be individual cognitive, emotional, and behavioural factors, but also possibly the wider contextual factors that shape individual responses.

## Further reading

Lopez, S.J., Pedrotti, J.T. and Snyder, C.R. (eds) (2015). *Positive Psychology: The Scientific and Practical Exploration of Human Strengths.* 3rd edition, Los Angeles: Sage.

This textbook presents an informed review of the history of the field, the evidence surrounding concepts such as personal strengths, resilience, pleasure, positive emotions (including happiness), optimism and hope, and the opportunities for intervention some of the evidence points to. Empathy and prosocial behaviour are also addressed, relevant to more recent challenges to the idea of positivity.

## Key papers

Helliwell, J.F., Huang, H. and Wang, S. (2016). New evidence on trust and wellbeing.

https://www.nber.org/papers/w22450.pdf

A working paper from the National Bureau of Economic Research provides a useful review of concepts and measures of social trust and their wellbeing associations using data from three large international surveys, the Gallup World Poll, the European Social Survey and the World Values Survey.

Taylor, S.E., Welch, W., Kim, H.S. and Sherman, D.K. (2007). Cultural differences in the impact of social support on psychological and biological stress responses. *Psychological Science*, 18: 831–7.

A fascinating and important review of a strong body of evidence pointing to cultural variations in support-seeking coping – read this if you are planning a social support intervention!

Uchino, B.N., Bowen, K., Carlisle, M et al. (2012). Psychological pathways linking social support to health outcomes: A visit with 'ghosts' of research past, present and future. *Social Science & Medicine*, 74: 949–957.

A review of thirty years of research (up to 2010 only however) examining the psychological mechanisms (e.g. of stress appraisals, affect) through which social support may achieve its' effects on many of the physiologically-based health outcomes described in this and other chapters. Some of their conclusions may surprise you.

## Weblinks

For personality assessment items based on a scientific collaboration to develop advanced measures of personality and other individual difference variables, go to the International Personality Item Pool at:

http://ipip.ori.org/ipip

# Chapter 13

# Managing stress

## Learning outcomes

By the end of this chapter, you should have an understanding of:

- cognitive-behavioural and mindfulness approaches to stress management
- ways of intervening at a population or organisational level to reduce work stress
- interventions of value in helping people to cope with the stress associated with a surgical operation

## Stress costs the National Health Service millions of pounds

No surprise in that, we hear you think. And, indeed, stress-related diseases do cost the British National Health Service (NHS) millions of pounds. But these are not the only cause of stress-related financial drain on valuable NHS resources – some can be directly influenced by the healthcare system itself. Staff sickness due to stress is estimated to cost the NHS in excess of £400 million a year (NHS Digital, 2020a). Less measurable is the impact of stress on patient recovery. Being in hospital and having an operation are both inherently stressful events: stress that may impact on patients' experience of pain, their use of pain medication, and even the time taken to recover from surgery. Conversely, simple interventions to reduce stress prior to an operation or giving patients control over pain medication have been shown to reduce the amount of pain medication used, and even reduce the time patients spend in hospital. Stress may be an ambiguous term, it may even be inherent in the experience of being a healthcare worker or patient but reducing the stress of both hospital staff and their patients may not only make their lives better but also actually save money.

## Chapter outline

Stress, they say, is all around us. Indeed, one of the most frequently reported problems in general practitioners' surgeries is tiredness as a symptom of stress. Other chapters in this book comment on the role of stress in the development or response to illness (Chapter 11 and 12 ☛) or how learning to manage stress can enhance mood, improve disease outcomes and reduce the experience of pain (Chapters 16 and 17 ☛). What they do not consider in any detail is how any changes can be achieved. This chapter addresses this issue from a number of perspectives. It starts by reviewing the basic cognitive-behavioural model of stress, before building on this and more complex models to introduce two distinct treatment approaches. The first, known as stress management training, adopts a traditional cognitive-behavioural approach. The second involves the use of mindfulness approaches to managing negative emotions. The chapter then considers approaches used to minimise stress in healthy individuals, both in the public at large and in the workplace. In this, it complements Chapters 5 and 6 ☛ and their consideration of health-promotion strategies. Finally, we consider how stress may be minimised when people face a specific stressor, surgical intervention in hospital, using relatively simple interventions.

# The fundamentals of emotional regulation

In this first section, we examine cognitive-behavioural theories of emotional regulation, which consider negative emotions including anxiety and depression to be the outcome of a variety of environmental and cognitive processes. The core of this approach links back to the fundamental work of clinicians such as Beck (1976) and is based on the assumption that our cognitive responses to events, not the events themselves, determine our mood. The experience of distress or other negative emotional states are a consequence of 'faulty' or 'irrational' thinking (see Figure 13.1). That is, they consider distress to be the result of *misinterpretations* of events or cognitions that exaggerate the negative elements within them and lose focus on any positive aspects of the situation.

Beck (e.g., 1976) referred to the thoughts that drive negative emotions as automatic negative thoughts (ANTs). They come to mind automatically as the individual's first response to a particular situation and are without logic or grounding in reality. Despite this, their automaticity means they are unchallenged and taken as true. He identified two levels of cognition. Surface cognitions are those we are aware of: the ANTs. We can access them and report them relatively easily. Underlying them are a set of unconscious beliefs about ourselves and the world, known as **cognitive schemata** (singular, schema) which influence our surface cognitions and, in turn, our emotions, behaviour and physiological arousal. Stress-evoking thoughts increase sympathetic nervous system arousal (see Chapter 8 ☛), evoke behaviour that may be more or less helpful in resolving the problem

**cognitive schemata**

set of unconscious beliefs about the world and ourselves that shape more conscious cognitive responses to events that impinge on us.

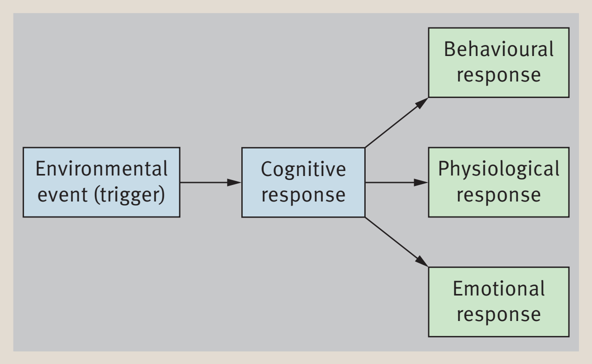


**Figure 13.1** A simplified representation of the event–stress process suggested by Beck and other cognitive therapists

an individual is facing, and result in the experience of negative emotions such as anxiety and depression. Beck identified a number of categories of thought that lead to negative emotions, including:

- *Catastrophic thinking*: considering an event as completely negative, and potentially disastrous: 'That's it – I've had a heart attack. I'm bound to lose my job, and I won't be able to earn enough to pay the mortgage.'
- *Over-generalisation*: drawing a general (negative) conclusion on the basis of a single incident: 'That's it – my pain stopped me going to the cinema – that's something else I can't do.'
- *Arbitrary inference*: drawing a conclusion without sufficient evidence to support it: 'The pain means I have a tumour. I just know it.'
- *Selective abstraction*: focusing on a detail taken out of context: 'OK, I know I was able to cope with going out, but my joints ached all the time, and I know that will stop me going out in future.'

A good example of how long-term schemata drive very stressful ways of responding to external events is provided by Price's (1988) cognitive model of Type A behaviour (see Chapter 12 ☛). From her clinical work with Type A men, she concluded that the schemata underlying Type A behaviour were low self-esteem and a belief that one can gain the esteem of others only by continually proving oneself as an 'achiever' and a capable individual. These underlying beliefs underpinned more conscious competitive, time-urgent or hostile thoughts.

Surface cognitions associated with Type A behaviour include:

- *Time-urgent thoughts*: 'Come on – we haven't got all day – I'm going to be late! Why is he so slow? Am I the only person who gets things done around here?'
- *Hostile thoughts*: 'That person cut me up deliberately! I'll sort him out. Why is everyone else so incompetent – they really are pretty stupid.'

Deeper (unconscious) schemata include:

- 'I can't say no to her request or I will look incompetent and I will lose her respect.'
- 'I must get to the meeting on time – whatever the cost – or people will think I'm incompetent and I will lose their respect.'
- 'People only respect me for what I do for them – not for who I am.'

So, somewhat paradoxically, behaviours that are generally seen as aggressive, confident, and self-serving may actually be driven by negative beliefs about the self and low self-esteem.

## WHAT DO YOU THINK?

The cognitive-behavioural model of stress assumes that stress lies within the individual. Stress arises from the misinterpretation of events that happen to us. But is this really true? It is possible to argue that while some stress may be the result of faulty thinking, stress can also be triggered by truly stressful circumstances. Most people would consider having a surgical operation, for example, to be a stressful event. Theorists such as Hobfoll have argued that many more general factors, such as being a single mother or holding down a demanding job, are universally stressful events. Arguments that socioeconomic status influences health through psychological processes discussed in Chapter 2 ☛ also suggest that there are broad differences in the degree of stress experienced across different social groups.

If these assertions are true, then, at least in some cases, stress truly may result from the environmental circumstances an individual is facing. Such arguments may lead us to question how relevant stress management techniques can be in these contexts.

The argument cognitive-behavioural therapists would marshal against this critique is that, while acknowledging the role of environmental factors as a cause of stress, some people cope with them better than others. There is individual variability in our ability to cope with the demands placed on us. The role of stress management is not to deny the role of the environment but to help people to cope with stressful circumstances they face as effectively as they can with the least possible emotional distress.

This seems to be a reasonable argument, but it leaves a number of questions for health psychologists. One particularly pertinent issue is how much effort we should put into changing the *sources* of stress and how much into changing people's *responses* to potentially stressful environments? Should we help some people to cope better with operations, for example, or try to make the processes before and after an operation less stressful for all? Often, teaching people to cope better with stressful situations is easier and cheaper than changing the causes of stress. But is it the best approach?

# Stress management training

Many health psychology interventions are focused on reducing the stress associated with living with chronic disease or life stresses that may be contributing to the development or maintenance of disease (see Chapter 17 ☛). The stress response described above suggests a series of factors that can be changed in order to reduce an individual's stress. These include:

- environmental events that trigger the stress response – or a series of triggers to longer-term stress;
- inappropriate behavioural, physiological or cognitive responses that occur in response to these events.

Most stress management programmes focus on changing people's reactions to events that happen around them or to them. Many simply teach relaxation to minimise the high levels of arousal associated with stress (see Chapter 11 ☛). More complex interventions try to change participants' cognitive reactions to these events. Few address the factors that trigger the stress response in the first place. This can be considered a serious limitation, as the most effective way of reducing stress is exactly that. Accordingly, we incorporate into our overview of **stress management training** a process of both identifying and changing triggers to stress as well as strategies for dealing with stressful thoughts, emotions and behaviour once initiated:

- Triggers can be identified and modified using problem-solving strategies.
- Cognitive distortions can be identified and changed through cognitive techniques, such as **cognitive restructuring** (see below).
- High levels of muscular tension and other signs of physiological arousal can be reduced through relaxation techniques.
- 'Stressed' behaviour can be changed through consideration and rehearsal of alternative behavioural responses.

From a stress theory perspective, therefore, these may be considered as involving both problem-focused and emotion focused strategies.

## Changing triggers

This is an often-neglected part of stress management training, perhaps because there is no standard intervention that can be applied. The triggers to each person's stress necessarily differ, as will any strategies they develop to reduce their frequency. Changing them involves first identifying situations that contribute to an individual's stress and then either changing their nature or reducing the frequency with which they occur. A simple strategy to reduce an individual's level of stress or anger while driving to work, for example, may be to start the journey earlier than previously so they feel less pressure during the journey.

One of the most frequently used approaches to identifying and changing triggers to stress was developed by

stress management training

a generic term for interventions designed to teach participants how to cope with stress.

cognitive restructuring

a reconsideration of automatic negative or catastrophic thoughts to make them more in line with reality.

Gerard Egan (e.g. 2017). His model of problem-focused counselling introduced in Chapter 6 ☛ can be adapted to coping with stress, so stress triggers are dealt with in three stages:

1. *Problem exploration and clarification*: what are the triggers to stress?
2. *Goal setting*: which stress triggers does the individual want to change?
3. *Facilitating action*: how do they set about changing these stress triggers?

Stress may have multiple sources, and some may be easier to change than others. It can be helpful to change relatively easy stress triggers before working towards those that are more difficult to change as the individual gains skills or confidence in their ability to effect change. Some changes can be achieved using personal resources already available to the individual. Others may require them to learn new skills in order to manage their stress more effectively. They may also benefit from learning to relax or reducing the frequency or type of any stress-provoking thoughts that contribute to their stress. It is to these taught skills that we now turn.

## Relaxation training

The goal of relaxation is to enable the individual to relax as much as is possible and appropriate while dealing with any stress they may be experiencing. This contrasts with procedures such as meditation, which often provide a period of deep relaxation or 'time out'. As well as the physical benefits, effective use of relaxation techniques can lead to an increase in actual and perceived control over the stress response; itself a valuable outcome. Relaxation may also increase access to calm and constructive thought processes, reflecting the reciprocity between each of the different stress components. Relaxation skills are best learned through three phases:

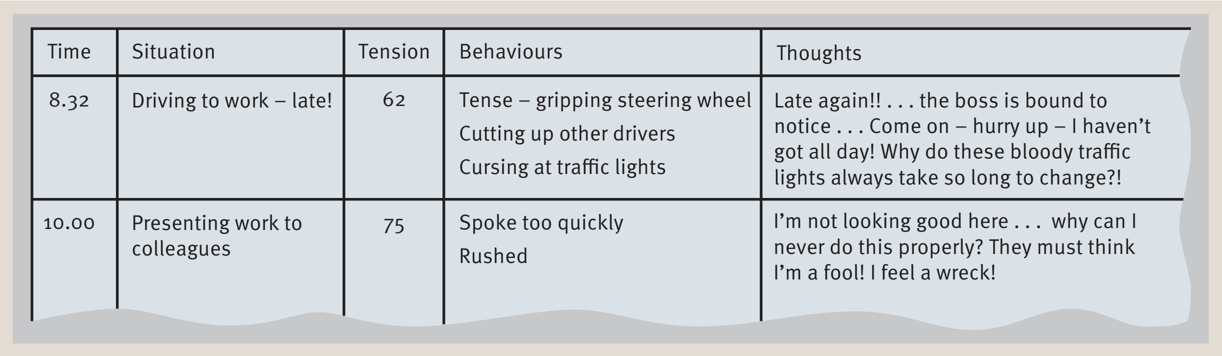
1. learning basic relaxation skills;
2. monitoring tension in daily life;
3. using relaxation at times of stress.

### Learning relaxation skills

The first stage involves learning to relax under optimal conditions: a comfortable and fully supportive chair in a quiet room. Ideally, a trained practitioner should teach the process of deep relaxation live. This can be augmented by continued practice at home, typically using taped instructions. Regular practice over a period of days, and sometimes weeks, is important at this stage, as the skills need to be well practised and relatively automatic before they can be used effectively in 'real life' contexts.

The relaxation process most commonly taught is based on Jacobson's (1938) deep muscle relaxation technique. This involves alternately tensing and relaxing muscle groups throughout the body in an ordered sequence. Over time, the emphasis of practice shifts towards relaxation without prior tension, or relaxing specific muscle groups while using others, to mimic the use of relaxation in the 'real world'. While practicing their relaxation skills, individuals can begin to monitor their levels of physical tension throughout the day. Initially, this serves as a learning process, helping them to identify how tense they are at particular times and what triggered any excessive tension. This may also help identify likely future triggers to stress and suggest when the relaxation procedures may be particularly useful. This process may be enhanced through the use of a 'tension diary', in which the individual records their level of tension on some form of numerical scale (0 = no tension, 100 = the highest tension possible) at regular intervals throughout the day or at times of particular stress. As a prelude to cognitive or behavioural interventions, such diaries may also focus on the thoughts, emotions or behaviour experienced at such times. Figure 13.2 provides an excerpt from a typical stress diary. As the individual begins to use additional strategies to combat their stress, they may add columns measuring their level of tension after the use of relaxation, the strategies they used to deal with their stressful thoughts, and so on.

After a period of monitoring tension and learning relaxation techniques, individuals can begin to integrate relaxation into their daily lives. At this stage, relaxation involves reducing tension to appropriate levels while engaging in everyday activities. Initially, this may involve trying to keep as relaxed as possible and appropriate at times of relatively low stress and then, as the individual becomes more skilled, using relaxation at times of increasing stress. The goal of relaxation is not to escape from the cause of stress but to remain as relaxed as possible while dealing with the particular stressor.



| Time | Situation | Tension | Behaviours | Thoughts |
|---|---|---|---|---|
| 8.32 | Driving to work – late! | 62 | Tense – gripping steering wheel<br>Cutting up other drivers<br>Cursing at traffic lights | Late again!! . . . the boss is bound to notice . . . Come on – hurry up – I haven't got all day! Why do these bloody traffic lights always take so long to change?! |
| 10.00 | Presenting work to colleagues | 75 | Spoke too quickly<br>Rushed | I'm not looking good here . . . why can I never do this properly? They must think I'm a fool! I feel a wreck! |

**Figure 13.2** Excerpt from a stress diary noting stress triggers, levels of tension and related behaviours and thoughts

## Cognitive interventions

Two strategies for changing cognitions are frequently employed. The simplest, known as self-instruction training, was developed by Meichenbaum (1985) and is targeted at surface cognitions. It involves interrupting the flow of stress-provoking thoughts and replacing them with pre-rehearsed stress reducing or 'coping' thoughts; so-called 'positive **self-talk**'. These typically fall into one of two categories: (i) reminders to use any stress-coping techniques the person has learned ('You're winding yourself up here – remember to relax, deep breaths, relax your muscles' and (ii) reassurance that the individual has previously coped effectively with their feelings of distress ('Come on, you've dealt with this before – you can again – keep calm – things will stay in control'). To make sure these are relevant to the individual, and to help to actually evoke these thoughts at times of stress, Meichenbaum suggested that self-talk should be rehearsed, wherever possible, before the stressful events occur; whether in a therapy session or minutes before an anticipated stressor.

A more complex intervention, known as cognitive restructuring, involves first identifying and then challenging the accuracy of stress evoking thoughts. It asks the individual to consider their beliefs as hypotheses, not facts, and to assess their validity without bias. This process may involve consideration of both surface cognitions and cognitive schemata, although the latter requires significant insight. Learning this skill often involves a process known as the Socratic method or 'guided discovery' (Beck, 1976). In this, the client identifies a number of stress-provoking thoughts that have recently occurred, and then challenges their accuracy under the guidance of their therapist. They may challenge their stressful assumptions by asking key questions such as:

- What evidence is there that supports or denies my assumption?
- Are there any other ways I can think about this situation?
- Could I be making a mistake in the way I am thinking?

Once the individual can engage in this process within the therapy session, they are encouraged to use the Socratic process at times when they experience stress in their daily lives (see also the discussion of the downward-arrow technique in Chapter 6 ☛).

self-talk

talking to oneself (internally) – can be negative and thus add to stress; therapeutically, individuals are taught to use self-talk in a way that helps them to keep calm.

## Behavioural interventions

The goal of behavioural change is to help the individual respond to any stress triggers in ways that maximise their effectiveness in dealing with the trigger and cause them minimal stress. Some behavioural changes may be relatively simple. Behaviour that reduces the stress of driving may involve driving within the speed limits, putting the handbrake on when stopped at traffic lights and taking time to relax, not cutting in front of other cars, and so on. Others may take practice: a person who becomes excessively angry, for example, may need to practice appropriately assertive responses in therapy sessions to prepare them for doing the same in 'real life'. Still others may have to be thought through at the time of the stress. The goal of stress management training is to teach individuals to plan and ensure their response to any potential stressor is one that minimises their personal stress. A simple rule of thumb is to encourage individuals to stop and plan what they are going to do, even if this takes a few seconds, rather than to jump into action without thought, as this typically leads to more rather than less stress.

## Stress inoculation training

In his approach called **stress inoculation training**, Meichenbaum (1985) suggested that the various strands of cognitive therapy described above could be combined so that, when an individual is facing a stressor, they concentrate on:

- checking that their behaviour is appropriate to the circumstances;
- maintaining relaxation;
- giving themselves appropriate self-talk.

In addition, he suggested that when a particular stressor can be anticipated, the opportunity should be taken to rehearse these actions before the event itself. Once in the situation, the planned strategies should be enacted. Finally, after the situation has occurred, time should be given to review what occurred and how any successes or failures can be learned from, rather than treated as triumphs or disasters that should be soon forgotten.

# Third-wave therapies

Historically, the stress management approach outlined above falls into what has become known as the second ‘wave’ of cognitive-behavioural therapies. The first-wave theories and treatments were based on Pavlov and Skinner’s conditioning theories and did not consider changing cognitions to be relevant to behavioural change. The second wave adopted a much more cognitive approach, viewing cognitions as central to both the development and treatment of emotional problems. Although most stress management interventions are still based on this approach, a so-called ‘third wave’ of therapies is now gaining increasing empirical validation and use in the treatment of emotional disorders. The key characteristic of this approach can be characterised by the phrase ‘Feel the fear but do it anyway’. It adopts a more behavioural stance, shifting the focus from changing cognitions back to directly changing behaviour.

Proponents of this approach come from a number of theoretical backgrounds. One leading approach, known as Acceptance and Commitment Therapy (Hayes et al., 2004) adopts a radical behavioural stance, while others such as meta-cognitive therapy (Wells, 2000) have further developed cognitive models to include more complex processes such as attentional bias, interrogation of long-term memories and so on (both approaches are considered in more depth later in the chapter). However, central to both these approaches is the notion that much emotional distress results from a failure of coping. Long-term distress is seen as a consequence of the continued execution of inappropriate coping responses in response to any stressor the individual is facing. Often these coping efforts involve avoiding the causes of distress, whether they be fearful thoughts or external stimuli. As a consequence the individual fails to learn that many fears are exaggerated, and that they could actually cope more effectively in the avoided situation than they believe.

A key goal of therapy is therefore to encourage the individual to engage in a feared behaviour, cope with the emotional or physiological responses they may experience while doing so, and through successful negotiation of the situation come to learn that there is actually nothing to fear. The fundamental difference between this and the second wave approaches is the therapeutic response to inappropriate, anxiety-engendering thoughts. Second wave therapies focus on the thought content and either try to modify inappropriate thoughts or nullify them by replacing them with self-instructions. By contrast, third wave therapies do not directly address the content of such thoughts: participants are taught to focus away or tolerate them rather than change them. A key strategy to facilitate this process involves the use of mindfulness.

stress inoculation training

a form of stress-reducing intervention in which participants are taught to control stress by rehearsing prior to going into stressful situations; participants are taught to relax and use calming self-talk (he approach was developed by Donald Meichenbaum).

## Mindfulness-based interventions

According to Buddhist learning, mindfulness is necessary on the road to enlightenment, and is achieved through the meditative process of focusing one's awareness on the present; not memories of the past or possible creations of the future. Through meditation, we learn that 'thoughts are just thoughts' that may or may not be true. We can also learn to ignore particular thoughts or to be aware of them without them evoking an emotional reaction. Bishop et al. (2004) proposed a two-component model of mindfulness:

- *Self-regulation of attention*: this involves being fully aware of current experience: observing and attending to thoughts, feelings and sensations as they occur, but not elaborating on these experiences. Rather than getting caught up in ruminative thoughts, mindfulness involves a direct non-judgemental experience of events in the mind and body as they occur. This leads to a feeling of being very alert and 'alive'.
- *An orientation toward one's experiences in the present moment characterised by curiosity, openness and acceptance*: the lack of cognitive effort given to the elaboration of the meanings and associations linked to our various experiences allows the individual to focus more on their present experience. Rather than observing experience through the filter of our beliefs and assumptions, mindfulness involves a direct, unfiltered awareness of our experiences.

Clearly, learning mindfulness is not simple, and most teaching programmes involve attending a number of classes spread over many weeks or months, or using an app (e.g. Calm) with a similar learning process. During meditation, participants learn to focus on a particular physical stimulus, such as a picture, or a sensory stimulus such as the sound of a repeated mantra, and to be aware of, but not focused on, unwanted intrusive sensations, thoughts or emotions. Participants also practise mindfulness during ordinary activities like walking, standing and eating. This process can help people to become aware of their thoughts but not be overwhelmed by them. Rather than challenge thoughts, practitioners of mindfulness learn to be aware of them, but only as a small, unattended part of their perceptual awareness which is still largely focused on the immediate experiences of the moment.

The most frequently cited method of mindfulness training is the mindfulness-based stress reduction programme of Kabat-Zinn (e.g., 2013). The full programme comprises an 8–10-week course for groups who meet weekly for around two hours for instruction and practice in mindfulness meditation skills, together with discussion of stress, coping, and homework assignments. An all-day (7–8 hours) intensive mindfulness session is usually held around the sixth week. Several mindfulness meditation skills are taught. For example, the 'body scan' is a 45-minute exercise in which attention is directed sequentially to numerous areas of the body while the participant is lying down with eyes closed. Sensations in each area are carefully observed. In sitting meditation, participants are instructed to sit in a relaxed and wakeful posture with eyes closed and to direct attention to the sensations of breathing.

Hatha yoga postures are used to teach mindfulness of bodily sensations during gentle movements and stretching. Participants also practise mindfulness during ordinary activities like walking, standing and eating. Participants are instructed to practise these skills outside group meetings for at least 45 minutes a day, for six days per week. Audiotapes are used early in treatment, but participants are encouraged to practise without tapes after a few weeks. For all mindfulness exercises, participants are instructed to focus attention on the target of observation (e.g., breathing or walking), and to be aware of it in each moment. When emotions, sensations, or cognitions arise, they are observed non-judgementally. When the participant notices that their mind has wandered into thoughts, memories or fantasies, their nature or content is briefly noted, if possible, and then attention is returned to the present moment. Even judgemental thoughts (e.g. 'This is a waste of time') are to be observed non-judgementally! An important consequence of mindfulness practice is the realisation that most sensations, thoughts and emotions fluctuate, or are transient, passing by 'like waves in the sea'.

### Mindfulness plus

Mindfulness can form a stand-alone intervention or be combined with other stress management approaches. Wells (2000) argued that emotional distress arises following an appraisal of a disjunction between an actual and desired state ('If I stay here, I am going to get really stressed', 'My angina is going to be triggered if I do any exercise'), and the development of plans to reduce or prevent this discrepancy from occurring. In the case of stress or anxiety (or the perceived health risk of exercising), these plans usually involve avoiding the situation that causes or contributes to these negative emotional states. This may reduce the immediate discrepancy between feeling fearful and the desired state of not being fearful. However, continued use of avoidance prevents the individual learning that the feared situation will not result in the expected harm. The goals of therapy include encouraging participants to engage in feared behaviours or enter feared situations in a graduated process, using skills such as mindfulness to help them cope with difficult thoughts or emotions that may occur at this time.

## Acceptance and Commitment Therapy

A second mindfulness-based approach is known as Acceptance and Commitment Therapy (ACT; pronounced ‘act’). According to Hayes et al. (2004: 143), ACT is a therapy approach that uses acceptance and mindfulness as well as commitment and behaviour change processes to teach increased psychological flexibility. ACT is rooted in radical behaviourism, as it assumes that psychological events (thoughts, emotions, behaviour) are the result of classical and operant conditioning processes. In addition, ACT does not consider thoughts or feelings direct behaviour. Change can be achieved through changing contextual variables or direct behavioural change rather than attempts to change internal processes such as cognitions, emotions, sensations, and so on.

ACT teaches the individual to be aware of ongoing private events (thoughts), but not to be driven by them: to be in touch with the present moment as fully as possible, and to either change or persist in behaviours in order to achieve valued goals. All ACT interventions aim to increase the individual’s flexibility in responding to situations they face. This flexibility is established through a focus on five, related, core processes: acceptance, defusion, contact with the present moment, values, and committed action.

- **Acceptance:** allowing oneself to be aware of thoughts, feelings, and bodily sensations as they occur, but not to be driven by them. The aim is to experience non-judgemental awareness of these events and actively embrace the experience. Therapy emphasises that attempts at inappropriate control are themselves stressful and maintain the distress one is trying to control: ‘control is the problem, not the solution’. Acceptance is taught through a variety of techniques, including mindfulness. Participants learn through graded exercises that it is possible to feel intense emotions or notice intense and bodily sensations without harm.
- **Cognitive defusion:** teaching participants to see that ‘thoughts are simply thoughts, feelings are simply feelings, memories are memories, and physical sensations are physical sensations’. None of these experiences are inherently damaging. Just as in the second wave of cognitive therapy, participants are taught that our thoughts form just one interpretation of events, and there are many others that may be equally appropriate to any situation. However, rather than attempt to identify incorrect thoughts and change them to a ‘correct’ interpretation of events, participants are encouraged to accept their presence, and not to try to change or control them.
- **Contact with the present moment:** contact comprises effective, open and undefended contact with the present moment. There are two features to this process. First, participants are trained to observe and notice what is present in the environment and in ‘private experience’ (i.e. their thoughts and emotions). Secondly, they are taught to label and describe what is present without excessive judgements or evaluation. Together these help establish a sense of ‘self as a process of ongoing awareness’ of events and experiences. Mindfulness is one technique through which this can be achieved.
- **Values:** the motivation for change. In order for a participant to face feared psychological obstacles, there needs to be a purpose for doing so. The aim of ACT is not simply to rid the person of their problems, but to help them build a more vital, purposeful life. This is a central element of ACT. Its goal is to enable the individual to progress towards valued life goals without being prevented from doing so by worries, emotions and other private events.
- **Committed action:** developing strategies for achieving desired goals. Individuals are encouraged to define goals in specific areas and to progress towards them. Progress, or lack of it, towards these goals becomes a key part of therapy.

Strosahl et al. (2004) identified a number of broad strategies to help people make changes in each of these domains. These included:

- helping the individual make direct contact with the paradoxical effect of emotional control strategies: i.e., the more you try to avoid painful thoughts, the more they may be experienced, and avoidance of feared situations leads to continued fear;
- using a graded and structured approach to acceptance: a form of systematic desensitisation in which participants learn acceptance of painful emotions (and other factors) in gradually more demanding situations;
- using various interventions, including mindfulness, to reveal that unwanted private experiences are not toxic and can be accepted without judgement;
- showing the participant how to pull away from worries or ruminations and come back to the present moment.

ACT is a complex therapy involving a variety of behavioural methods as well as the use of stories, metaphors and mental exercises to encourage change. As such, the approach cannot be fully considered within the present chapter. Interested readers may find the primer edited by Harris (2019), listed at the end of the chapter, a useful further reader. However, the key underpinning of their approach is that the primary process of change is to engage in previously avoided behaviours or refrain from previous ineffective and problematic coping behaviours, to learn to cope or reduce the distress involved in doing this through the use of mindfulness, and thereby learn that the feared consequences will not occur. As such, despite many differences in philosophy and approach, both the cognitive approach of Wells and the behavioural approach of the ACT therapists have much in common.

# Preventing stress

## Using stress management strategies

There is clear evidence that second wave stress management programmes can significantly reduce stress and improve wellbeing. In addition, they have been shown to impact on a variety of biological processes known to be affected by stress. Both Urizar et al. (2019) and Sannes et al. (2015), for example, found differing stress management programmes to be effective in reducing both perceived stress and levels of the stress hormone cortisol (see Chapters 8 and 11 ☛) in individuals with differing health problems. There is also increasing evidence that mindfulness-based interventions can reduce stress among healthcare workers (Ghwadra et al., 2019) and people with a range of health problems. Indeed, mindfulness-based interventions dominate the recent literature, examining ways of reducing stress among a range of health problems. It's not always successful though. A meta-analysis by Schell et al. (2019), for example, found evidence of only marginal gains across 14 trials of mindfulness in women with breast cancer. In addition, a second meta-analysis (Ghielen et al., 2019) found similar gains following cognitive behaviour therapy and mindfulness-based interventions in people with a range of neurological disorders. Choosing between second and third wave therapies may not be easy, and in the end may be based on individual preferences.

We consider the impact of stress management on wellbeing and biological processes in people with health problems in more detail in Chapter 17 ☛. The next sections, however, examine stress management interventions conducted with healthy individuals in a specific context – the workplace.

## Managing stress in the workplace

Stress management interventions clearly have the potential to provide significant benefit to those who take part. But only a very small proportion of the public who have the potential to benefit are likely to take the time and trouble to attend workshops or other training programmes. Health psychologists and others have therefore turned to other methods of reaching out to those who may benefit from stress management. One of the most important approaches they have adopted is to develop strategies for reducing stress in more 'captive audiences', perhaps the most important of which has been people at work.

There is significant and rising pressure on employers to provide staff with the skills to manage stress effectively. In the UK, this has become increasingly important as the Health and Safety Executive (https://www.hse.gov.uk/stress/), which determines safety standards in the workplace, gives employers a legal obligation to protect the emotional as well as physical wellbeing of their employees. Their reasons for this policy include data indicating that:

- over half a million individuals in Britain experience work-related stress at a level that is making them ill, while nearly one in five think their job is very or extremely stressful;
- work-related stress, depression or anxiety accounts for an estimated 11 million lost working days per year in Britain;
- levels of work stress are rising;
- teachers and nurses have particularly high prevalence of work-related stress.

Most published attempts to reduce stress in the workplace have involved running stress management training at the workplace using methods outlined earlier in the chapter. That is, they have tried to help attenders to cope more effectively with the demands placed upon them. These appear to be effective. Summarising the relevant data in their meta-analysis, Richardson and Rothstein (2008) reported limited but significant benefit for those attending cognitive behavioural stress management programmes. More recently, Bartlett et al. (2019) found evidence of gains on measures of stress, anxiety, distress, wellbeing and sleep from their synthesis of data from trials of workplace mindfulness programmes. In a more specific review of mindfulness interventions among nurses, van der Riet, Levett-Jones and Aquino-Russell (2018) found evidence of a modest benefit on measures of stress and burnout, but also noted that many of the studies were relatively small, and more studies in larger populations would be of benefit. Some caution should also be found in the results of Mino et al. (2006) who found improvements in mood following a stress management programme, but little effect on the specific stress associated with work, reflecting the difficulties of achieving change in the context of challenging work environments.

There have been a number of criticisms of individually targeted stress management programmes within the workplace. This type of programme usually attracts only between 10 and 40 per cent of the workforce, as a result of factors including lack of interest, the timing of sessions, lack of managerial support, and incongruency between what is taught and the actuality of the work environment (e.g., Ilvig et al., 2018). In addition, the majority of people who do attend seem to have relatively few stress-related problems, while many anxious individuals do not attend, perhaps because they feel that they will gain little from such courses or do not want to air their problems in front of their colleagues. Noblet and Lamontagne (2006) had more philosophical concerns, as they suggested that the approach can be seen as labelling those with high stress as somehow not coping, and avoids employers having to modify any work-related causes of stress.

An alternative approach to helping individual workers manage workplace stress involves changing the context in which individuals work to make it less inherently stressful. Identifying and changing organisational causes of stress is more complex than providing stress management classes but can have significant implications for an organisation. Table 13.1 indicates the variety of potential stressors that may influence the stress of people working in a hospital, some of which are common to many work situations, some of which are unique to working in healthcare settings. Each may become a target of systemic interventions designed to reduce their associated stress.

**Table 13.1** Some sources of stress for hospital workers

| Professional issues | Patient issues | Work issues |
|---|---|---|
| Over-promotion | Distressed patients or relatives | Shift work |
| Under-promotion | ‘Difficult’ patients or relatives | Poor working conditions |
| Interactions with colleagues | Dying patients | Too high a workload |
| Interactions with management | Complaints made against staff | Work intruding on home time |
| Working beyond knowledge level | | Lack of social support |
| Lack of management support | | Inadequate equipment |

**Photo 13.1** Sometimes even students can experience stress!!

*Source*: Creativa/Shutterstock.

## Case history

Changing any organisational factors may impact on the stress of hospital workers; but working out where and how to intervene at an organisational level is not easy. However, the process used by one of the authors (PB) to reduce stress in a group of hospitals provides an example of how this might be done. The process involved:

- identifying causes of stress in the working environment;
- identifying solutions to this stress from those most involved;
- developing a process of change to address the issues raised.

The first two stages of the intervention involved running a series of focus groups with different staff throughout the organisation. These were led by a health psychologist, who worked with the management of the hospital but who was not part of the management team. Many focus groups were run with key hospital staff, including cleaners and porters, nurses, managers, clerical workers, and people from the paramedical professions such as occupational therapists and physiotherapists. In each of these meetings, comprising about six people, attenders were invited to identify factors in their working environments that adversely affected their 'quality of life' at work. If problems were identified – and they inevitably were – they were also asked to identify any solutions to those problems. These meetings were intended to last up to one hour but often went on longer and were extremely productive.

Each of the issues and solutions put forward in the groups were then arranged into a set of common problems (and perhaps solutions) in a document that formed the basis of the next phase of the intervention. Problems raised included major systemic problems, such as:

- a poor computer network system;
- poor timing of the hospital bus provision (it did not fit in with shift times);
- very poor parking facilities, making transport to and from work difficult;
- inadequate crèche facilities;
- the organisation of various groups of wards in the hospital into competing rather than cooperating units;

- a working culture among management that punished people who did not work significant overtime.

Interestingly, the solutions that some workers used to manage their stress impacted on other workers by increasing *their* dissatisfaction and stress. One example of this was that the management team in one hospital had moved its offices away from the wards to avoid what they thought of as too much day-to-day contact with the ward staff and to allow them to concentrate on more long-term planning. As a result, the management group felt less stressed and more able to get on with their job effectively. By contrast, and unbeknown to the management team, the ward nurses were angry and disillusioned as they felt this was an example of management blocking off contact they felt vital to their effective running of the wards.

Once the problems and solutions were documented, these were taken to a small committee of senior managers, which formed a response to the needs. It did so by grouping the issues raised into three broad categories:

1. those likely to have minimal effect, but relatively easy to instigate;
2. those likely to have a significant effect, but more difficult to instigate;
3. those likely to have a significant effect, but impossible to instigate.

Clearly, the interventions focused on the first two of these categories. Changes made included increasing the size of the crèche and lengthening its opening hours so that it was more useful for shift workers, changing the times of the hospital buses to make them more user-friendly, and initiating a new hospital computer system over a number of years. However, any interventions need not necessarily be on such a large scale. One example of this was provided by a nurse manager, who noted that her staff often arrived late or very close to the time of their morning shift. When she asked them why, she found that these were predominantly single mothers who had to leave their child with a childminder on their way to work. Because childminders would only take children from a time close to the beginning of the shift, this put these nurses under significant time pressure. If the traffic was good between the childminder and hospital, they got to work on time; if the traffic was busy or delayed, they were late to work. The simple solution to the problem was to start the shift 15 minutes later and to record the handover.

## RESEARCH FOCUS

### How long can the effects of stress management training continue?

Herr, R.M., Barrech, A., Riedel, N. et al. (2018). Long-term effectiveness of stress management at work: effects of the changes in perceived stress reactivity on mental health and sleep problems seven years later. *International Journal of Environmental Research and Public Health*, *15*: 255.

The study reports an impressively long follow-up to a study previously reported in which lower middle management attenders attended a series of seminars designed to teach them to manage work-related stress more effectively and to obtain support from colleagues. The group selected were considered as potentially highly stressed as they form a, sometimes difficult to manage, buffer between people involved in production and higher-level management. The intervention, involving both psychodynamic and cognitive behavioural approaches proved effective in the short-term. This study investigated its long-term outcomes. The original study comprised a randomised controlled trial, with a waiting list control, who received the intervention after the control period. Accordingly, all participants in the present study had received the intervention.

#### Method

##### *Participants*

A total of 174 male participants (66 per cent of those invited) were workers in an international manufacturing plant in Dusseldorf, southern Germany, who had some degree of leadership responsibility aged between 18 and 65 years, and no serious illnesses impacting on their ability to work. Data reported in the present study were obtained at baseline before the intervention, and 2- (n = 131) and 9-year follow-up (n = 102).

### *Measures*

- *Stress Reactivity Scale*: measured the degree of stress associated with individual's responses to stressors in six domains: (i) *work overload*: feeling nervous, agitated, irritated; (ii) *social conflicts*: feeling affected, annoyed, upset; (iii) *social stress*: feeling nervous, losing self-confidence; (iv) *failure*: feeling annoyed, disappointed, down; (v) *anticipatory reactivity*: feeling nervous, tense before important task or decision; and, (vi) *prolonged reactivity: difficulty relaxing/unwinding*. An overall stress reactivity score is computed by totalling the sub-scale scores.
- *Hospital Anxiety and Depression Scale*: measured anxiety and depression (note, despite the name, both scales are measures of everyday mood).
- *Sleep problems*: two items measuring difficulties in getting to sleep and difficulties in remaining asleep through the night.
- *Covariates*: included socioeconomic status, work characteristics (shift work, levels of responsibility), lifestyle factors (smoke, exercise, BMI).

### *The intervention*

The intervention comprised a series of two-day, 'group-orientated prevention seminars' with eight teaching units, followed by two refresher booster sessions. It used psychodynamic, conflict-and emotion-focused principles, and cognitive behavioural techniques to foster awareness of, and insight into, stressful workplace situations, and to provide tools to better deal with typical stressful situations such as work overload, social conflicts, problems with social evaluation, and failure at work. Attention was also given to strengthening individual resources by for example, encouraging social networking and social support among participants.

## Analysis

Changes in perceived stress reactivity from measures before and after the intervention were transformed into change scores. Linear regression was then used to determine the association between change scores and outcomes of depression, anxiety, and sleep problems at follow-up. Four regression analyses were conducted for each outcome, measuring the relationship between change scores and the dependent variables (mood etc) after adjusting for an increasing number of variables:

i. age, education, partnership, and participation in and year of the stress management intervention
ii. work characteristics (shift work, personnel responsibility)
iii. lifestyle factors (smoking, physical activity, BMI)
iv. chronic diseases and critical life events

In this way, it was possible to determine the relationship between changes in stress reactivity and the mood and sleep outcomes, and whether and how much these remained significant after taking into account the effect of an increasing range of alternative explanatory variables. In Table, the beta values and the variance each variable explains (the $R^2$) is reported for the dependent variable of depression.

Linear regressions revealed that a reduction in stress reactivity to social conflicts and in prolonged stress reactivity predicted lower depression scores seven years later (Model 4: social conflicts beta = 0.41; $p = 0.048$; $R^2 = 19\%$; prolonged reactivity beta = 0.80; $p = 0.003$; $R^2 = 24\%$;).

In a series of similar analyses, prolonged reactivity was the sole significant predictor of anxiety: beta = 0.62; $p = 0.012$; $R^2 = 25\%$. Finally, improvements in overall stress reactivity scores (beta = 0.07; $p = 0.017$; $R^2 = 17\%$), social conflicts (beta = 0.29; $p = 0.005$; $R^2 = 18\%$), and prolonged reactivity (beta = 0.35; $p = 0.01$; $R^2 = 17\%$) were positively associated with sleep quality.

**Table 1** linear regressions examining the relationship between change measures of stress reactivity and subsequent measures of depression.

| | Depression | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Model 1 | | Model 2 | | Model 3 | | Model 4 | |
| | B | $R^2$ | B | $R^2$ | B | $R^2$ | B | $R^2$ |
| Overall reactivity | 0.091 | 0.142 | 0.091 | 0.144 | 0.097 | 0.175 | 0.092 | 0.180 |
| Work overload | −0.186 | 0.132 | −0.180 | 0.133 | −0.118 | 0.158 | −0.140 | 0.168 |
| Social conflicts | 0.393 * | 0.149 | 0.394 * | 0.151 | 0.415 * | 0.182 | 0.412 * | 0.189 |
| Social stress | 0.328 | 0.133 | 0.343 | 0.136 | 0.362 | 0.166 | 0.343 | 0.171 |
| Failure at work | 0.489 | 0.146 | 0.483 | 0.146 | 0.461 | 0.172 | 0.491 | 0.183 |
| Anticipatory reactivity | 0.147 | 0.117 | 0.149 | 0.119 | 0.138 | 0.147 | 0.088 | 0.155 |
| Prolonged reactivity | 0.776 ** | 0.204 | 0.797 ** | 0.209 | 0.812 ** | 0.236 | 0.795 ** | 0.238 |

* $p < 0.05$
** $p < 0.01$

## Discussion

These data show the impact of changes in stress reactivity following the problem-focused part psychodynamic, part cognitive behavioural two-day seminar plus follow-up. The original study showed evidence of significant changes on key stress measures, in particular stress reactivity, and this study showed that these changes were predictive of changes on measures of mood and sleep quality for up to nine years subsequently. Importantly, these changes were independent of factors including sociodemographic and economic factors, as work characteristics, chronic disease, lifestyle and life events. So, they seem robust and direct. It is impressive that changes following a relatively brief intervention have lasting influence within an occupational sphere and beyond). It seems that managers may significantly benefit from this sort of provision as required learning.

An empirically evaluated programme similar to the case history was reported by Bourbonnais, Brison and Vézina (2011). Their systemic intervention targeted a range of health professionals in a large Canadian hospital and involved the intervention team meeting with a range of staff in meetings lasting up to three hours. Through them, they identified six types of problem to address: team-work and staff morale, staffing processes, work organisation, training, communication and ergonomics. Problems ranged from high workloads for untrained nurses, nurses lacking confidence in dealing with doctors' negative attitudes and lack of stability in care teams. 'Doable' solutions were developed for each of these and other identified problems. By three-year follow-up, much had changed. However, as is so often the case, many new problems had arisen over this time, including senior nurses leaving and not being replaced, the appointment of a new hospital director, increases in very difficult to treat infections within the hospital, one hospital experiencing significant financial problems, and a further re-organisation of the hospital staff. Despite these problems, compared to individuals who were not affected by the changes, improvements were found on five of nine measures developed for the programme including increased supervisor support and reduced burnout due to work. No gains were found on measures of psychological distress, sleeping problems, and co-worker support. More recently, Norman and Basu (2018) used a series of focus groups to identify organisational contributors to stress among clerical staff working in a UK hospital Emergency Department. The groups both identified problems and possible solutions, which where possible were then implemented. Over time, staff reported feeling more in control of their working environment although there were no significant changes in their work demands or social support.

More focused interventions have focused on specific stressors such as workplace bullying. In a review of the effectiveness of such interventions, Gillen et al. (2017) examined the effectiveness of organisational interventions designed to promote civility, respect and engagement, negative behaviours awareness training. These followed the CREW process, which included six months of weekly meetings of 10–15 workers and facilitators during which each group explored understandings of civility and respect, and how these principles could be established in their workplace followed by less frequent meetings designed to facilitate continued engagement with the programme. Unfortunately, despite the effort involved, the impact of the intervention type was modest, achieving reductions in supervisor incivility and victimisation but not co-worker incivility and victimisation or, indeed, self-reported incivility perpetration. More positively, the intervention was associated with a decrease in absences from work.

## IN THE SPOTLIGHT

Although the obvious health challenge following the COVID-19 pandemic relates to the physical consequences of infection, a further consequence may be long term mental health problems. And these may be from multiple sources, including: (i) survivors of the infection who have experienced highly traumatising healthcare including ventilation, (ii) people with long-covid at risk for depression and anxiety due to continuing symptoms, (iii) the health professionals involved in the care of covid-19 patients and who have witnessed high levels of mortality and personal suffering, (iv) people with existing mental health problems exacerbated by lockdown, as well as, (v) new 'cases' directly as a result of health anxieties, social isolation and so on. Each of these groups may require significant and differing types of support, perhaps lasting years after the pandemic has abated. This need has been recognised by the UK government and NHS. It is to be hoped in the economic challenges facing the country as it comes out of the pandemic that this hidden need is not forgotten and is appropriate.

At an individual level, the stress associated with the COVID pandemic is an unusual form of stress. Not only is its cause relatively unique, the psychological challenges it results in are also unusual. Coping with a crisis can result in a single, effective response. Sometimes called a 'surge capacity' or response (Enns, 2021), this powerful response to stress is time-limited and quickly exhausted. But coping with COVID-19 has presented a very different challenge. Stress in this context, even for those who have not been infected with the virus, has come in repeated waves, with the overall experience lasting months or even years. There may be repeated peaks, but the troughs are also pretty stressful. So, how do we cope with, or build resilience against, long-term grinding stress? According to Enns, we need to build active resilience. She identified three sets of coping strategies through which we can achieve this:

1. Choose a practical and realistic habit that will increase wellbeing. Anything from walking the dog to drinking more water. According to Enns, the key here is to keep these habits small and meaningful. Changes may not be immediately obvious, but the regularity of these routines can help build patterns that increase stamina.
2. Make one positive connection each day. According to Enns, the time we have on our own or with limited positive social interactions can lead us to focus on our worries and concerns and to miss social and other interactions that may interrupt this process or provide more positive thoughts. So, she recommends seeking at least one positive interaction each day (involving positive expression of gratitude, appreciation or humour), whether live, online or message/email. This, she claims will enhance wellbeing and resilience.
3. Pause and really focus on 'now'. Anxiety and stress pull our attention to the future, past, and worries of 'What if. . . ?!' One key means of managing this involves taking regular times in the day to become fully immersed into the immediate present— to feel and smell the rice you are cooking, the smell of the air in the morning, the rhythm of walking (how you hold your body, the flow of air, the feel of the ground under your feet, and so on). Here, we have

the basics of mindfulness or, as Seligman may call it, flow.

These positive coping responses to build resilience may sound simple, but they form part of what Martin Seligman, a leading researcher in depression and then positive psychology, called his PERMA model of happiness. According to Seligman (see positivepsychology.com), resilience is based on five personal attributes:

- experience of positive emotions including hope, joy, love and compassion;
- engagement in the present – the experience of flow;
- positive relationships;
- meaning: that is, feeling of value and worth - feeling part of something that is wider than the self;
- accomplishments: feelings of achieving goals and a sense of working towards meaningful achievements and competence through endeavour and perseverance.

This may be further developed through optimism, nutrition, and exercise. The modern movement towards positive psychology embraces these approaches and cannot just prevent unhappiness (the previous goal of most psychological interventions), but instil happiness.

The effectiveness of this systemic approach to reducing stress was summarised by Montano, Hoven and Siegrist (2014) in their meta-analysis of the effectiveness of interventions designed to improve the health of workers reported in thirty-nine intervention studies. The studies addressed a range of stress outcomes, including mental and physical health measures as well as some musculo-skeletal measures more relevant to changes in physical working conditions. Those addressing mental health issues reported outcomes such as mental distress and sleep, mental health, stress-related health problems and ‘burnout’. Nineteen of the 39 studies reported significant benefits of the interventions, and those with multiple targets including issues such as working hours and the intensity of work, organisational stressors including the degree of control over the job, the structure of work hierarchies, and ‘material conditions’ (noise, vibrations, ergonomics) were nearly three times more effective than those with limited targets. Brand et al. (2017) found 11 studies targeting healthcare settings and utilising approaches targeted at the working environment or up-skilling senior managers in ways of enhancing staff health and wellbeing. All interventions proved reasonably effective, with those that measured physical and mental health showing some gains. In addition to these personal gains, such interventions have been shown to enhance teamwork and communication, patient safety and quality of care and the overall efficiency and cost-effectiveness of organisations (Giga et al., 2018).

Reasons for the failure of interventions often involve organisational constraints on change, including a lack of enthusiasm for change among relevant management and workers, external events such as job turnover, organisational restructuring and merging of companies, and a failure to establish the intervention properly within the workplace. These ubiquitous problems illustrate well the challenge of establishing organisational change in any large organisation.

# Minimising patient stress in hospital settings

## Preoperational preparation

Having an operation is a stressful event, whether it is a small operation conducted under local anaesthetic or a larger one involving a period of unconsciousness and a significant period of recovery. It should not be surprising, therefore, that levels of anxiety can be high both before and after an operation. This anxiety is both unpleasant for the individual concerned and can add to the complications they experience. It may increase the amount of painkilling medication they take, the degree to which they need reassurance both before and after the operation, and even the time necessary for them to stay in hospital. As a consequence, a number of researchers have attempted to identify ways of minimising this distress. While the stress management approaches described above may be appropriate under such circumstances, healthcare staff and patients rarely have the time to teach or learn these strategies; although hypnosis has proven effective with adults (Montgomery et al., 2007) and children (Liossi et al., 2006). Accordingly, a very different approach has been taken to help people to cope with this specific type of stress.

**Photo 13.2** The calming presence of a parent can help children to relax and cope better with any concerns they may have about their operation

*Source*: Shutterstock.

Many studies have shown that we feel less anxiety when faced with potentially stressful circumstances if we can be given some degree of control over them. These findings have led health psychologists to examine whether giving patients undergoing surgery some degree of control over their situation will reduce the amount of stress they experience. Clearly, patients cannot have much control over their anaesthetics or surgery. Such things really should be left to the experts! So, in this case, 'giving control' has been interpreted as 'keeping people informed about what is happening to them'. This is thought to reduce anxiety by minimising the fear of the unknown. If patients know what to expect, they may understand better and be less alarmed by any experiences they have. If patients are told, for example, they will experience some pain after their surgery they will be less alarmed and less likely to think that things have gone wrong if they do experience pain. A number of studies have examined the effectiveness of providing two sorts of information to patients prior to them having surgery:

1. *Procedural information*: telling patients about the events that will occur before and after surgery; having a pre-medication injection, waking in the recovery room and having a drip in their arm, and so on.
2. *Sensory information*: telling patients what they will feel before and after surgery: that it is normal to feel some pain following surgery, they may feel confused when they come round from the anaesthetic, and so on.

The overall picture is that these interventions usually work, and may both reduce anxiety and improve rehabilitation outcomes such as pain management, ambulation, engagement in physiotherapy and even day of discharge (e.g., Ong et al., 2009). Despite a generally positive story, such interventions are not always successful, however. Luck et al. (1999), for example, found that showing a video about the procedure a week before patients were given a **colonoscopy** reduced anxiety in the period leading up to the procedure. In a subsequent study of the same

colonoscopy

a minor surgical procedure in which a small piece of bowel wall is cut from the colon; this can then be tested for the presence of malignant cells.

procedure, however, the same research group found no such benefit (Pearson et al., 2005).

## Matching patient needs

One explanation for these mixed findings could be that the effect of the intervention is relatively weak and is not always found. Another explanation could be that the intervention works for some people, and not others. What may be as important as the type of intervention, is matching it to the characteristics of the patients receiving it. Patients who typically cope with stress by using avoidant coping strategies may benefit, for example, from receiving less information than those who typically cope through the use of problem-focused strategies (see Chapter 11 ☛), and vice-versa. This hypothesis was tested by Morgan et al. (1998), who gave people identified as primarily ‘information seekers’ or ‘avoiders’ either sensory information about the nature of a forthcoming colonoscopy or no information. Patients who were given information congruent with their coping style (i.e., minimal information for ‘avoiders’; maximal information for ‘seekers’) reported less anxiety prior to the procedure than those who were given incongruent information. They also scored lower on a measure of ‘pain behaviour’ made by nursing staff during the procedure, although participants did not report any differences in pain during the procedure or differ in their use of sedative drugs. These data suggest that:

- People who usually cope using problem-focused strategies benefit from information that helps them to understand their experience and to actively interpret their experience in relation to information they are given.
- People who usually cope using avoidant, emotion-focused, strategies benefit most from not being told what to expect, and perhaps being helped to develop strategies that help them distract from the situation.

Overall, despite these potential different outcomes of standard interventions based on individual coping differences, the evidence for the effectiveness of pre-operative procedures including information provision as well as more ‘interventionist’ approaches such as relaxation and cognitive therapy is generally positive, albeit to a modest degree. In a meta-analysis of over 100 studies, Powell et al. (2016) concluded that psychological preparation techniques were associated with lower postoperative pain, length of stay (reductions average half a day) and negative mood compared with controls. The type of intervention appeared to have little impact on the outcome, except for post-operative pain for which more interventionist approaches may be more effective.

## Working with children and parents

Much of the more recent work in preparing people for surgery has focused on helping children and their parents rather than the adult targets considered above. Studies that have focused on children have shown that a variety of techniques may be of benefit. Perhaps the simplest has simply been the provision of storybooks (Tunney and Boore, 2013) or more recently video games (Kumar et al., 2019) while awaiting surgery, which have achieved successful outcomes in both younger and older children on measures of peri-operative pain, stress and anxiety.

In a more complex intervention, Hatava et al. (2000) randomly assigned children and parents to one of two interventions designed to reduce anxiety before an ear, nose or throat (ENT) operation. In the first condition, they were given written or verbal information by a nurse two weeks prior to surgery. This included information about general hospital rules, routines and the date of the operation. This acted as a form of **placebo intervention** as there is little here that would have been expected to reduce anxiety other than meeting the nurse that may be involved in their care. The second group was given a more complex intervention comprising the same information two weeks prior to the operation followed by a visit to the ENT department the day before surgery. During this visit, each child and parent met the anaesthetist who would be at the operation and took part in a group session led by a nurse in which they were shown the operating theatre and lay on the operating table. They were also shown the equipment that would be used during anaesthesia and were encouraged to play with it in order to minimise its threat and increase familiarity. They were then shown the procedure that would occur on the day through role-play using a doll. This complex intervention

**placebo intervention**

an intervention designed to simulate a psychological intervention but not believed to be a specific therapy for the target condition.

resulted in significant benefits. Both younger and older children reported less fear and anxiety prior to the surgery. In addition, their parents reported more satisfaction and less anxiety than those who did not receive the intervention.

One final approach used in a similar context by Liossi et al. (2009) compared the effects of a local skin cream anaesthetic alone or combined with the use of self-hypnosis involving suggestions including numbness, topical anaesthesia, and glove anaesthesia (pain free area mirroring that of a glove over a hand) prior to a painful procedure (in this case taking blood). This combined intervention proved superior on measures of anxiety and procedure related pain, and its efficacy has been supported by the positive conclusions of a later meta-analysis of this and similar approaches used to help young people cope with painful procedures (Birnie et al., 2018).

Tackling the issue from another perspective, interventions that target parents may benefit both parent and child. Kain et al. (2007), for example, compared the effectiveness of standard care, parental presence alone prior to surgery, a complex family-based intervention including a parental training package on supporting their child prior to and during anaesthesia induction, and oral anti-anxiety medication. Parents who received the family intervention were less anxious than those in the other conditions. In addition, children of these parents were less likely to experience delirium following surgery, required less anaesthesia in the recovery room, and were discharged from the recovery room more quickly than children in the other conditions. Despite the potential success of these latter types of intervention, their relative complexity and the commitment required from health professionals makes them less likely to be adopted in the real world of work, where the video distraction techniques may be equally effective and much more time efficient for preparing children for both anaesthesia and painful procedures (Bernie et al., 2018).

## SUMMARY

This chapter has examined a variety of approaches to stress management and contexts in which it has been conducted. Systemic interventions that target whole organisations can be used as a preventive approach. More individual approaches based around specific therapeutic approaches may benefit people experiencing general stress. Finally, simple procedural information may benefit people facing the stress of an operation where there is little time (or need) to use these more complex interventions.

1. Stress management 'classes' based around second and third wave interventions provide a potentially useful intervention, attendance is likely to be limited, and health psychologists and others have targeted larger and more 'captive audiences' in organisations.
2. Managing stress at this level can involve a variety of approaches depending on the organisational causes of stress. Stress management interventions should follow an audit of stressors, and target environmental issues that both contribute to stress and can realistically be changed in the context of the particular workplace.
3. Cognitive-behavioural interventions targeted at reducing stress involve changing:
   - triggers to stress, using, for example, the problem-focused approach of Egan;
   - the cognitive precursors to stress, using the self-instruction and cognitive restructuring approaches of Beck, Meichenbaum and Ellis;
   - the physiological response to stress using relaxation methods, including the modified Jacobsen technique;
   - the behavioural reactions to stressful situations using Meichenbaum's stress inoculation and role-play techniques.
4. Mindfulness-based, third wave, approaches to stress management take an opposing view. Rather than directly attempting to change cognitions, they teach participants to acknowledge any stress engendering thoughts they may have, but not to make these the focus of their attention. This can be achieved using mindfulness or acceptance techniques, and allows the individual to engage in previously stressful behaviours, and learn through experience that they can cope while doing so.
5. Finally, providing relevant information to help people to understand and cope with the stress

of hospital procedures such as operations may reduce distress and pain and facilitate rehabilitation following surgery. However, its benefits vary according to individual differences in coping style.

- Patients who are typically problem solvers benefit most from the provision of information.
- Patients who typically cope with stress using avoidant strategies may be helped best by teaching them distraction techniques.

## Further reading

Elkin, A. (2013). *Stress Management for Dummies*. New York: Wiley.

A fairly irreverent but useful guide to managing your own stress.

Wells, A. (2011). Metacognitive Therapy for Anxiety and Depression. New York: Guilford Press.

Harris, R. (2019). ACT Made Simple: An Easy-to-read Primer on Acceptance and Commitment Therapy. Oakland, CA: New Harbinger Publications.

Kabat-Zinn, J. (2013). Full Catastrophe Living, Revised Edition: How to cope with stress, pain and illness using mindfulness. London: Piatkus.

Three key texts of modern approaches to managing stress.

Hesketh, I. and Cooper, C. (2019). Well-being at Work: How to Design, Implement and Evaluate an Effective Strategy. London: Kogan Page.

Examines both the consequences of organisational stress and how these may be reduced. Looks at organisations rather than individuals.

## YouTube

One of the best ways to learn about therapies is to see therapists in action and explaining their use of relevant theory and techniques. Without this explanation in any video, we may get a good idea of the types of problems people face, but unless you already have some familiarity with the techniques, it can be difficult to really understand the subtleties of what is going on.

PsychotherapyNet on YouTube (https://www.youtube.com/user/PsychotherapyNet) has a host of world leading therapists talking about and showing a range of therapies in action, usually in relatively small clips.

Some of the best YouTube channels which show the basics of CBT include those with Christine Padesky and the Beck Institute for Cognitive Behaviour Therapy. Do a live workshop with either of these, and it will cost a fortune, so benefit from their freebies on the YouTube.

Type 'stress management' or 'stress management training' into any search engine, and you will get thousands of hits. Few are useful resources though, as most are links to commercial sites who want your money before you can access information. You could try this site, though (although no promises!): http://www.mindtools.com/

WEB

Visit the website at **go.pearson.com/uk/he/resources** for additional resources to help you with your study.

# Part III

# Being ill

# Chapter 14

# The impact and outcomes of illness: patient perspective

## Learning outcomes

By the end of this chapter, you should have an understanding of:

- the psychosocial impact of illness
- the diverse nature of coping responses in the face of illness
- demographic, clinical and psychosocial influences on patient outcomes
- models of patient adjustment, subjective wellbeing and QoL
- QoL as a multidimensional, dynamic and subjective construct
- challenges to assessing subjective health status and quality of life

## Physical health problems have more than a physical impact

At the crux of health psychology is the simple fact that we, as humans, respond in complex and varied ways to the experience of symptoms, illness, communication with healthcare professionals and treatments. While our individuality is what makes life exciting, it also presents challenges to traditional healthcare systems and personnel. Healthcare professionals seek to treat the illness but are faced with not just physical symptoms but an array of emotional, behavioural and social correlates and consequences, which they may feel less equipped to deal with. While there is increasingly integrated care, for example, where clinical health psychologists are increasingly embedded within hospital multidisciplinary teams in a pain, cancer or rehabilitation services and national guidelines commonly make recommendations for the commissioning of psychological services alongside medical services; however, this does not yet happen consistently across all age groups and all health conditions. As this chapter and the next will show, the psychosocial impact of illness has implications not only for emotional wellbeing and quality of life, but also for future physical health. Therefore, health psychologists must demonstrate to health commissioners the 'added value' of recognising the psychosocial impact of illness and the resulting needs of patients and their families.

## Chapter outline

Illness is a dynamic process, beginning with perception of symptoms or a diagnosis which continues or changes over time as a function of the disease pathology, treatment possibilities and the responses to illness by the person affected and those around them. In Chapter 9 ☛ we introduced the self-regulation of illness model and described the influence of how and what we think about symptoms on subsequent coping responses, and in Chapters 11 and 12 ☛ we described the many individual and social factors that influence a person's responses to a range of life stresses, including illness. In this chapter we focus more on the impact of illness and the outcomes a person may experience- not just in terms of physical functioning but on emotional wellbeing, adjustment, and quality of life (QoL).

We highlight illness-specific, personal, psychological and social factors that play a role in adjustment to illness, with coping theorised, and often evidenced, as playing a key role. The wide range of coping responses made by individuals facing the challenge of illness and the functions these serve is described. Rather than focusing only on negative responses or outcomes of illness, this chapter will also present evidence of personal growth or benefit-finding in the illness experience and consider how positive appraisals and emotions may influence the perception of gain.

Given the subjectivity of many constructs, we also adddress issues of how to measure illness outcomes, and in particular the multidimensional, dynamic and subjective concept of quality of life.

Many of those affected by illness do not cope alone and so this chapter leads nicely into the subsequent one which addresses the impact of illness on significant others, and on the relationship between patients' and carers' beliefs, experiences, and outcomes.

## The prevalence of chronic disease and multiple morbidity

It is estimated that, in Europe, approximately 50 million people are living with multiple chronic conditions with the ageing population increasing this over time; yet our services tend to be set up for single medical specialties, rather than address challenges around the physical and psychosocial impact of multi-morbidity (Albreht et al., 2016; Rijken et al., 2018). Further driving recent calls for more integrated care are other alarming figures, such as that one-third of the population aged over 15 years old and almost a quarter of the working age population live with a chronic health condition, and roughly 65 per cent of those at retirement age have at least two such conditions (European Chronic Disease Alliance, ECDA 2019). Worryingly, the rising levels of obesity in childhood will also cause future increases in chronic disease incidence in adulthood. In addition to personal impact, physical illness and its consequences carry significant societal costs, including loss of many potential productive life years to the economy with people dying early, or working less and retiring earlier (see Busse et al., 2010 Report for Europe), and increased demands on healthcare systems (ECDA, 2019). Caring for people with multiple comorbid conditions is complex as conditions vary as do their treatments- consider for example, living with diabetes which focusses on health literacy and self-management, possibly lifestyle change typically managed in the community, and compare to cancer, which can involve multiple medical interventions and hospital management (Albreht et al., 2016). In fact many of our services, at least in the hospital setting (as opposed to community based general practices in primary care), are set up to work with one type of illness, e.g. respiratory conditions, musculoskeletal conditions, cancers, mental health issues etc. Such 'silos' of care provides the context within which an individual becomes ill, receives treatment, and goes onto experience either recovery, remission or chronic illness. As health psychologists we can perhaps not influence care provision quickly, but we can build up and provide evidence as to the importance of addressing the 'whole' of individual illness experience, and the benefits of person-centred care, informed and shared decision-making. Rijken and colleagues (Rijken et al. 2017) noted in their review of 112 practices in 24 countries of the EU (including Iceland, Norway and Switzerland), as part of the ICARE4EU project specific to those with multiple chronic conditions, that non-disease specific practices offer more comprehensive care, with greater emphasis on patient needs, patient involvement- and likely therefore offer a more holistic, biopsychosocial approach, which we as health psychologists also advocate!

## The challenges of illness

Illness presents individuals with many challenges that may change over time, depending upon the illness, the treatment, the individual's cognitive, behavioural and emotional responses, and the social and cultural context in which the illness occurs. Illness is a complex process, illustrated by Morse and Johnson's (1991) generic model of emotional and coping responses from the onset of symptoms through to living with a chronic illness. Individuals are considered as having to deal with:

1. *Uncertainty:* in this period the individual tries to understand the meaning and severity of the first symptoms.
2. *Disruption:* this occurs when it becomes evident to the individual that they have a significant illness. They experience a crisis characterised by intense stress and a high level of dependence on health professionals and/or other people who are emotionally close to them.
3. *Striving for recovery:* this period is typified by the individual attempting to gain some form of control over their illness by means of active coping.
4. *Restoration of wellbeing:* in this phase, the individual achieves a new emotional equilibrium based on an acceptance of the illness and its consequences.

A similar series of stages of response to a cancer diagnosis was proposed by Holland and Gooen-Piels (2000). Initial feelings of disbelief, denial and shock, where some people challenge the health professional's ability or diagnosis and try to defend themselves from the implications of the diagnosis are followed by a one-to two-week period of *dysphoria* where individuals gradually come to terms with the reality of their diagnosis. At this time significant distress and related symptoms such as insomnia, reduced appetite, poor concentration, anxiety and depression may be experienced; but as information given about treatment is gradually processed, hope and optimism may emerge to compete with the more distressing thoughts. After this, adaptation emerges and the person develops long-term coping strategies in order to maintain equilibrium.

Although these models propose a staged adaptive process, not all individuals will move through stages smoothly nor achieve emotional equilibrium or a stage of acceptance and adaptation. Elements from different 'stages' may co-occur: for example, a person may experience significant distress even when actively coping with their illness. Individuals may also move backwards and forwards between stages and reactions, for example shifting their focus from one of cure to one of 'healing', in which they try to resolve life issues and achieve some completion of their life's achievements. They may still maintain hope at this time, but rather than hope for a cure they may shift towards hope for a 'good' or pain-free death (Little and Sayers, 2004).

'Staged' approaches have been criticised for the manner in which they categorise patients and create expectations of responses to serious illness events (e.g. Hale, 1996; Crossley, 2000). While staged theories provide a useful starting point for those working with the ill or the dying, recognition is needed that individuals may not neatly 'fit' into any one defined stage. Living with illness requires a process of adjustment, and, as described in Chapter 9 ☛ with regards to the Common Sense Model of Illness and illness self-regulation, or Chapter 11 ☛ in terms of coping with stress theories, many factors influence how an individual responds to stress, as presented in Chapter 12 ☛. The nature of an illnesses impact will determine the wellbeing, quality of life and adjustment outcomes an individual experiences, but there are personal, cultural, cognitive and emotional influences on this relationship, as we outline in this chapter.

# The impact of illness

In this chapter we address a selection of common and potentially life-changing health conditions. As a general principle, it is important to distinguish between illness with a sudden onset, such as a stroke or heart attack, and those with a less acute and more insidious development such as cancer, multiple sclerosis or dementia, as the speed in which life is changed can have important consequences. The physical consequences of illness for individual functioning, disability, social integration and role performance are particularly illustrated in a whole chapter dedicated to discussing the experience of pain (Chapter 16 ☛). The physical consequences of various illnesses and any associated treatments have inevitable implications for how a person will cope and adjust to these consequences, and how they cope will, in turn, impact on emotional, functional and social outcomes. The ultimate physical outcome of illness is of course death, and many research studies therefore also assess survival rates. However, of perhaps more interest to psychologists is the *variation* in the physical and psychosocial morbidity associated with illness – the ability and disability, the quality of life and wellbeing that those living with illness experience, and the extent to which a person is able to function independently or interacts with care providers (see Chapter 15 ☛ for a discussion of caregiving). Starting at the beginning, when bodily changes or signs (see Chapter 9 ☛) enter the realm of healthcare, we see the emotional impact in terms of the effect of receiving a diagnosis of illness.

## Prevalence of depression and anxiety

In terms of two of the major killers in Western society, heart disease and heart attack, it is estimated that one-fifth or more of sufferers will experience levels of depression above cut-offs indicating clinical disorder during hospitalisation, with severe anxiety typically exceeding one-third (Lichtman et al., 2008; Murphy et al., 2020). Depression and anxiety symptoms often persist for up to a year following the event onset, for example, as seen in an Australian study of a mixed sample of 911 cardiac patients (MI, acute coronary syndrome, unstable angina, or undergoing coronary artery bypass graft (CABG) surgery) where at 6–12 months after the event anxiety remained at 27 per cent (compared to 43 per cent when assessed close to event onset), and depression remained at 15 percent (compared to initial 22 per cent) (Murphy et al., 2020). Among stroke patients a systematic review and meta analysis of 61 studies representing over 25,000 stroke patients reports a 25 percent prevalence of depression at 1 to 5 years post stroke (95 per cent confidence interval 16–33 per cent) with variations depending on whether samples are assessed in hospital or at home or in the community or on the timing of assessment (Hackett and Pickles, 2014). For many stroke patients, significant levels of emotional distress (anxiety and/or depression) persist for many months, with uncertainty about the future, fear of recurrence and role changes also common (McCurley et al., 2019). Further dramatic change is experienced by those experiencing other forms of brain injury, for example traumatic brain injury (TBI) following an accident, with the multiple losses (cognitive, emotional and behavioural) often also resulting in depression (prevalence up to 33 per cent) and generalised anxiety (prevalence up to 41 per cent, see review by Schwarzbold et al., 2008).

Within cancer populations, the overall prevalence rates of emotional distress have been reported as high as 70 per cent, with both depression and anxiety considered to be present in the majority of patients at some point (e.g. Fallowfield et al., 2001; Zabora et al., 2001). However, this depends on whether global distress or more specific mood states are assessed, on the timing of assessment, and possibly on the stage of the disease of the specific patients assessed although findings for the latter are inconsistent – for example, diagnostic levels of depression were seen in between 8 and 25 per cent of cancer patients with advanced disease (Hotopf et al., 2002); however a review of 100 studies found that disease stage did not inevitably predict greater distress (Massie, 2004). Some cancers do, however, consistently associate with higher distress: for example, among 304 pancreatic cancer patients – a cancer carrying a high mortality risk – almost 29 per cent reported elevated depression compared to 18.5 per cent of 7,749 patients with other cancers, even when controlling for gender and age (Clark et al., 2010).

A systematic review of studies comparing adults with diabetes with healthy control participants found two–three times more depression (Roy and Lloyd, 2012), and significantly more emotional distress, generalised anxiety disorder, and anxiety symptoms in those with diabetes, with the latter being seen in 40 per cent of the diabetic sample (Grigsby et al., 2002). Diabetes distress describes a broader, illness specific condition, different from 'clinical depression' (Fisher et al., 2012), which relates to the burden of demands of managing the illness, worry and emotional burden, impact on interpersonal relationships, and those with caregivers and health professionals and thus reflects adjustment (Berry et al., 2015). For those living with this chronic, controllable, but potentially life-threatening illness, daily self-management is required, which includes seven domains (Greenhalgh et al., 2011): having knowledge of one's condition; controlling diet; taking insulin; foot care; exercise; testing and monitoring glucose levels daily; attending check-ups. These require a significant investment of time and effort by the diabetic patient. Greenhalgh's qualitative analysis highlighted that diabetes self-management generated several 'storylines': for example, 'becoming sick'; 'rebuilding a spoiled identity'; 'living a disciplined and balanced life'; 'mobilizing a care network' and 'navigating and negotiating in the healthcare system'. These emotional and behavioural tasks, elicited by the person's illness, can take on a life of their own, above and beyond symptom management.

In illnesses where a certain degree of stigma is attached, for example those with HIV infection and AIDS, the social meanings surrounding the illness can be associated with the higher levels of reported distress. Valente's (2003) review concluded that between 20 and 30 per cent of people with HIV are clinically depressed at some stage in their illness, other studies have reported 70 per cent having moderate to high anxiety (Cohen et al., 2002). Perhaps unique to those with HIV infection, the presence of what have been identified as 'punishment beliefs' (i.e. where HIV infection is considered by the individual to be a 'punishment' for 'inappropriate' behaviour) have been associated with relatively high levels of depression and relatively low self-esteem (Safren et al., 2002). Such beliefs reflect possible internalisation of early beliefs or prejudices about HIV and likely routes of infection, such as injecting drug use or unprotected homosexual sex.

## Points to consider

Various factors are important when considering figures related to distress, anxiety and depression in various illnesses.

Firstly a range of psychosocial factors in addition to disease features predict long-term emotional outcome: for example, patient satisfaction with healthcare and confidence in recovery predicted depression at six months and three years following acute stroke (Morrison et al., 2000b, 2005). Secondly, it is important that studies assess patient's prior history of mood disorders, and also wider factors such as their socioeconomic status and financial position. These factors are also associated with increased anxiety and depression, as seen in Murphy's review and in relation to HIV where high levels of background stress, low levels of personal resources and social support, and poor coping skills also contribute to depression (e.g. Catz et al., 2002). These factors also predict depression among healthy populations.

Thirdly, and interestingly, while at many stages of the illness experience, distress, anxiety and depression are shown to be higher than that seen in the general population (see a review of arthritis, asthma, cancer, diabetes mellitus, osteoporosis and stroke studies, Clarke and Currie, 2009), levels assessed after the initial year or so, are not necessarily inconsistent with those found in the general population. figures suggest an estimated lifetime prevalence of 9.6 per cent for mood disorders broadly speaking, and 12.6 per cent for depression (Steel et al., 2014). However, while depression may be less common among cancer 'survivors' (a term generally referring to those 5+ years post-treatment completion), these individuals face the uncertainties that survivorship brings:

recurrence; the possibility of developing other cancers; lasting effects of treatment; and the potential of a shortened life expectancy, thus anxiety or worry remains prevalent (e.g. Deimling et al., 2006).

In conclusion, both among children and adults, chronic illness typically increases the prevalence of depression and anxiety. Studies of pediatric psychology additionally highlight the impact of disruption to a child's routine, altered environments (e.g. hospitalisation, removal from parents or school) and changes in role, function and ability, on aspects of a child's sense of self, as well as their emotional wellbeing (e.g. Coyne, 2006; Gannoni and Shute, 2010; Christie and Khatun, 2012; Compas et al., 2012 (review)).

## Emotional responses to illness

### Emotional reaction to diagnosis

In terms of the response to diagnosis, perhaps because of the perceived threat to life, but also due to its prevalence, the majority of studies seem to address those receiving a cancer diagnosis, with reactions typically described as catastrophic and highly emotional. One qualitative study reports how one woman, recently diagnosed with breast cancer, described herself as standing 'with one foot in the grave, the other on the edge' (p. 115), with other individuals describing themselves quite literally as 'fighting for their life' (Landmark and Wahl, 2002). In a rare study of men diagnosed with penile cancer (Bullen et al., 2010) one man describes how, on being told of his diagnosis he 'just broke down and I don't know what he was talking about 'cos when you mention cancer, well you have got six weeks to live'. While for some the stark reality of the health threat led to quick acceptance of the need for a positive decision about treatment, including surgery (e.g. 'if they do not amputate this penis you are dead, all right, so you have two choices: you live or you die. I said "cut it off"'), beyond the reassurance surgery offered regarding cancer removal, longer-term negative consequences were seen in terms of self-concept, 'it starts to dawn on you then: you are no longer . . . you're half a man'. Interestingly, women assessed within two weeks of diagnosis with breast cancer who reported higher cancer-specific stress responses (but not general stress responses) were more likely to exhibit 'post-traumatic growth (PTG)' at a six-month follow-up (Tedeschi and Calhoun, 2004). The authors suggest that perhaps some early challenge of illness promotes subsequent positive growth. We discuss 'post-traumatic growth' in a subsequent section as it is not solely arising from a diagnosis.

Negative emotional reactions commonly follow diagnosis of many conditions, including those with life-threatening illnesses such as sudden-onset brain injury (Gracey et al., 2008), heart disease (e.g. Murphy et al., 2020; Polsky et al., 2005), stroke (e.g. Hackett and Pickles, 2014), or life changing diagnoses such as diabetes (Berry et al., 2015) or a positive HIV diagnosis (Valente, 2003; Moskowitz et al., 2009). For some conditions, the response of those diagnosed today possibly differs from that of those diagnosed in earlier decades or centuries; for example, receiving an HIV diagnosis today compared to when the virus was first identified in the 1980s when no antiretroviral treatment was available, or receiving a TB (tuberculosis) diagnosis now compared to in the nineteenth century before the discovery of antibiotics. Different responses to diagnosis may be due to the changes in personal and social expectancies attached to such conditions as much perhaps as to the improved prognosis of those examples.

### Loss of 'self'

Chronic illness can also bring about a sense of 'loss of self' (Charmaz 1983, 1991) to the sufferer. This is exacerbated by the necessity of living a restricted life due to symptoms, by social isolation due to physical limitations, by struggling to function in the world as previously or by fears of others' response to their 'new state'. One area of research where perceived stigma and judgement of others has been associated with challenge to a sense of self, significant distress and reduced quality of life is that conducted among those with 'visible' conditions, including facial scarring, burns, disfigurement or even the use of assistive technology, such as wheelchairs, assistive pets. We address these issues in the 'Research focus'.

Negative responses of others can sometimes lead to perceptions of the self being discredited, or to perceiving oneself as being a burden on others by being unable to fulfil one's 'normal' social roles and tasks (Cloute et al., 2008; Band et al., 2015). Illness often forces the person to redefine themselves, from a 'healthy' person to one with limitations, and this can reduce feelings of self-worth or self-esteem. There is evidence that empowering a person to hold on to their pre-illness sense of identity, keeping the illness as something separate to this, and learning to 'let go' of what the person can not change and accommodating the illness, rather than having an identity consumed can be beneficial to one's adjustment and valuing of oneself (Aujoulat et al., 2008). Such a distinction has implications for those working with patients with a view to enhancing control – there are aspects to hold on to, and others to let go, and, as stated previously in this textbook, perceived control beliefs have to be realistic if they are to be most helpful. In a similar vein, Jones et al. (2011) found that, among those with acquired brain injury, personal change in terms of developing a strong sense of self-identity encompassing a sense of survivorship, and strong social networks, mediated the negative effects of severe head injury on life satisfaction. Curiously, those with more severe head injury had higher life satisfaction and wellbeing which was explained by their having done greater 'identity work' resulting in a stronger self-identity, and improved social relationships. These factors likely interact, and, although this was not a longitudinal study, such data point to the importance of gaining positives from adversity. Related to this sense of identity and separation from the illness is the notion of 'illness centrality', i.e. the extent to which a person incorporates an illness into their self-concept. Helgeson and Novak (2007) found illness centrality to be higher among female adolescents with type 1 diabetes than males, and related to poorer psychological wellbeing, and also, in a later study, illness centrality was related to poorer adjustment among women with breast cancer (Helgeson, 2010). It has been proposed that adopting high illness centrality will have further negative consequences for those where there is associated stigma, with implications for disclosure, support-seeking and the like (Fisher and Chaudoir, 2010).

## RESEARCH FOCUS

### Visible difference in illness and disability

Sharratt, D., Jenkinson, E., Moss, T. et al. (2019). Experiences of living with visible difference: Individual and social reflections. *Health Psychology Update*, 28: 16–26

Squires, L.A., Williams. N. and Morrison, V.L. (2019). Matching and accepting assistive technology in multiple sclerosis: a focus group study with people with multiple sclerosis, carers and occupational therapists, *Journal of Health Psychology*, 24: 480–494

As Partridge and Pearson (2008) described in a moving article in *The Psychologist* about their own experience of disfigurement, 'liking and living with 'different' outsides can be very challenging' (p. 490). However it has also been suggested that compared to more 'visible' illnesses or conditions, people with 'invisible conditions, for example chronic kidney disease have 'nothing to show for it' (Bristowe et al., 2019, p. 4), thus undermining their access to a 'sick role' with its rights for support.

Do people however benefit from the sick role or the consequences of visible difference?

The following two articles were selected because they examine 'visible difference', firstly arising from a health condition, secondly arising from the use of Assistive Technology. For reasons of length, the studies are summarised quite brutally to address the point of this 'Research focus', however please do seek out the full papers!

### Study 1

#### *Introduction*

Research from the team at the Centre for Appearance Research at the University of the West of England at Bristol, has highlighted that 'visible difference' arising from an altered appearance or disfigurement (either congenital or acquired) presents significant challenges to those affected. The extent of the visible difference appears less strongly associated with adjustment than do the person's subjective evaluations of their 'difference'. Critical to these evaluations are perceptions of others' responses, which may include perceived stigmatisation. The primary aim of this study was to examine appearance related experiences and their impact upon a person's life.

### Method

Semi-structured interviews were conducted either online, by phone, or face-to-face depending on participant choice, with 22 individuals (16 women, 6 men; age range 25–64, average 43 years) with a visible difference (14 had acquired their visible difference; 8 had a congenital condition). Conditions included those that were typically visible, such as cleft lip/palate, facial scarring or birthmark; and those not typically visible to others such as breast cancer-related scarring, or alopecia where a wig is worn.

Interviews were recorded, transcribed verbatim and analysed using inductive thematic analysis as appropriate to a study seeking understanding of individual experiences.

### Results

Five themes were generated, each with several subthemes; two are presented in this paper which are:

| Theme | Subtheme | Example codes |
|---|---|---|
| Personal reflections on looking different | Becoming one with difference | Reduced confidence<br>Positive growth |
| | Hiding away | Cover up difference<br>Avoidance |
| | This lonely planet | Others not understand<br>Lack support |
| Our socially situated appearance | Appearance as projection | First impressions<br>Judgement |
| | Being public property | Intrusion<br>Assumptions |
| | Searching for comparative normality | Downward comparisons<br>Upward comparison |

The first theme highlights the impact of visible difference upon a person's thoughts, emotions and behaviours, the second theme highlights how appearance is considered to be a social phenomenon which shapes social interaction. Much of the data presented suggests a negative impact, for example, one participant notes how '*I am quite self-conscious and I am quite sensitive. I can take offence quite easily. I do look for trouble. It's definitely affected me*' while another notes how '*I'd say walk a mile in my shoes when I feel that I can't leave the house, which is kind of difficult to do really isn't it*?'. The presented quotes also highlight how others are unable to understand and therefore support them in dealing with the consequences of visible difference. For some this results in hiding away in order to minimise their visibility – either by covering up their difference with clothes (e.g. scarring, psoriasis) or a wig (alopecia), or by avoiding social situations altogether: '*Walking into a pub is my worst . . . along with high school, is the worst thing, not that I go to pubs and that's probably why I don't*', or '*If I do were short sleeved stuff, short sleeved attire that's when a) I feel most ill at ease and b) when I'm more likely to catch criticism, or, erm, horror or aversion for other people*'.

Participants felt that their 'self' was projected by their appearance and that they were implicitly judged by others on that basis. As one participant with facial scarring observed as an analogy to her experience: '*You kind of assume someone who's fat is lazy, which is not always the case really*'. Other people's response in terms of intrusive stares or unwanted questions etc, made participants feel like public property – however, a minority report how their difference was less noticed by others than they perhaps worried about. For others their visible difference has fostered positive growth, for example: '*If I wasn't born with a cleft lip and palate I wouldn't have the confidence or the determination that I have now*.'

### Discussion

Appearance was central to these participants' lives. Of note is that the reactions of others on the basis of their appearance, while difficult to deal with, seemed almost expected by participants given how ingrained appearance and body image was understood to be within current society. Notably, stigma was sometime more expected than experienced, however anticipation of the negative response of others could lead to avoidant behaviour.

This links onto the second paper, where narratives around acceptance of assistive technology also generated data relating to the responses of others

## Study 2

### Introduction

Multiple sclerosis is a condition characterised by loss of balance and functional impairment, pain, cognitive and emotional changes and fatigue. Assistive technologies are available which intend to reduce the negative impact of MS by supporting the person with activities of daily living, enhancing mobility, independence etc. However many devices go unused and thus their benefits go unaccrued which seems counter-intuitive. While research has primarily examined device-related factors in explaining this, the current study took a psychological perspective.

### Method

Four focus groups were held using a semi-structured topic guide; two with adults with MS (ten females, four males; age range 43–74 years), one with informal carers, and one with Occupational Therapists.

Focus groups were recorded, transcribed verbatim and analysed using thematic analysis (Braun and Clark, 2006) appropriate to exploration of the experiences and perceptions of participants.

### Results

Only those findings related to the theme of acceptance (or not) of AT and to the issue of visibility/invisibility are highlighted here. Three themes were identified which formed a chronological narrative from prior to, during, and following the use of AT:

- Critical MS events (e.g. progression of symptoms, waiting for a diagnosis or care; public reaction; progression of required AT):
  - ‘I started off one of my feet used to drag and then the other one but I ended up having a stick then two sticks and I have had crutches. I have got a wheelchair if I need to get any distance.’
  - ‘It’s very difficult for them (other people) because they’re it and well and we look alright . . . with Rose and Archie at least you can see they’re in a wheelchair but with me I’m just sitting here looking like there’s nothing wrong with me so I think it’s difficult then for my family to understand there’s something wrong with me.’
- Matching AT for continued use (acceptance of MS and of AT; Realistic expectations; Therapist responsiveness)
  - ‘That’s the trouble really . . . we all feel too independent sometimes and don’t want to be seen to be not able to do it. . . and I think it depends on the character that you are that determines whether you will use this thing.’
  - ‘People tend to have this idea that if they’re using equipment they’re giving into a condition. I get that a lot.’ (OT)
- The impact of AT which formed a chronological narrative from prior to, during, and following the use of AT (promoting or losing independence, stigma and embarrassment, redefining the carer):
  - ‘I don’t need those . . . I do. All the things [my OT] thought of, I now need (pause) it’s embarrassing in a way but there we are.’
  - ‘She’s probably brain-dead’ or ‘she can’t talk to us because she’s in a wheelchair’ . . . and they used to give the funny looks and all that and I’m thinking ‘what are you looking at?’

### Discussion

The most commonly used AT in this sample were mobility aids and it was seen that these had a hierarchy- from one stick to two sticks to a manual wheelchair to an electric wheelchair. Some PwMS were reluctant to use AT as they wished to lead a ‘normal’ life and remain independent without the use of often visible devices which were considered to increase anticipated or received stigma. The importance of using AT in order to achieve independence will require acceptance by the PwMS (and family carers) of its need and it’s benefits, and sympathetic handling of issues around perceived or received stigma in the responses of others.

## Overall discussion

Both of these studies raise the issue of social responses to illness and disability, and to the fact that for some individuals, living with daily challenges arising from disfigurement or disability, being ‘invisible’ may be preferred to a situation where they are exposed to negative responses of others. Such findings challenge the idea presented at the start of the ‘Research focus’, that visible illness at least ‘allows’ a person a sick role and concomitant support- visibility is not necessarily something that is sought. Both studies do also highlight however the importance of acceptance of self, and of one’s appearance or disability, as acceptance is generally associated with positive indices of adjustment, as described elsewhere in this chapter.

## Emotional reactions to the COVID-19 pandemic

Notably, during the first six months of 2020 during the COVID-19 pandemic, global prevalence estimates arising from a systematic review and meta-analysis of observational study data from 32 countries, found a global prevalence of depression 28 per cent; 26.9 per cent for anxiety, 50 per cent for global distress, 24.1 per cent for post-traumatic stress symptoms, 36.5 percent for stress, and 27.6 per cent for sleep problems. Furthermore, a wide variability in levels was observed according to regional socio-economic indicators, inequalities and pandemic preparedness (Nochaiwong et al., 2021). Within a US survey, depression symptom prevalence increased threefold from before the pandemic and during, with again, clear social inequalities (Ettman et al., 2020).

## Emotional reactions to treatment and hospitalisation

Not everyone will willingly submit themselves to hospital care if it is necessary, nor take on the ‘sick role’ and the depersonalisation and loss of control that can often accompany entering large institutions such as hospitals. Fear of anaesthetic, of treatments which confine (e.g. MRI scanners; Bolejko et al., 2008) or which involve pain and discomfort, all require sensitive pre-procedural information (e.g. Uman et al., 2008; Smolderen and Vingerhoets, 2010) (see Chapter 13 ☛). Pre-surgical anxiety in both adults and children is high and has been shown to influence post-surgical outcomes such as wound healing (Rokach and Parvini, 2011) and where treatments are repeated and ongoing: for example, courses of chemotherapy or dialysis, patients report feelings of anticipatory anxiety and anticipatory nausea (i.e. feeling worried and unwell just at the thought of entering hospital for the treatments) (Pandey et al., 2006; Rosco et al., 2010). During the active treatment phase of their illness, cancer patients potentially face a variety of stressors, including significant side effects such as nausea, fatigue and weight loss. Distress at this time can be complex while individuals weigh up the unwanted effects of treatment against the benefits of symptom reduction and survival gains, and their perceptions and expectancies of the treatment, as well as the perceived severity of symptoms, play a role (Thuné-Boyle et al., 2006).

As noted, some treatment interventions create not just health benefits but also significant challenges, such as undergoing chemotherapy, or a kidney transplant. For some, choices have to be made about which treatment to undergo – for example, while the majority of cancer-affected individuals choose to continue with treatment, a small minority do decline or withdraw from it. Treatment may also be declined when at risk of illness, for example, Lovegrove et al. (2000) found that, of 106 women at high familial risk of breast cancer attending a breast care clinic and asked to take part in a trial of tamoxifen (a synthetic, non-steroidal agent with tumour-limiting benefits in an unaffected breast), half refused to participate. Those refusing tended to be younger, found the information about tamoxifen as a potential preventive treatment harder to understand than those who took part, knew more about lifestyle risk factors, and saw fewer benefits of the drug. If a demanding treatment is not thought to have significant benefits, then saying no to it is a patient’s right.

This can be illustrated further through examination of the experience of those with end-stage chronic kidney disease between conservative kidney management (CKM) and dialysis. There is evidence that dialysis may not necessarily improve older people’s quality of life (e.g. Selman et al., 2019) and about 15 per cent of people with advanced kidney disease who do not start dialysis most are likely to be older with comorbidities and higher dependence (NHS Improving Quality, 2015). For these individuals, i.e. whereby a patient receives full supportive and multidisciplinary care (medical, psychological, social and spiritual, but excluding dialysis) CKM may better facilitate quality of life. In a prospective study conducted in the Netherlands, a functional decline within six months of starting dialysis was observed in patients aged 65 and over (Goto et al., 2019). In addition patients have reported being unhappy at having started dialysis with indications that the choice to start it often reflected the doctor or family's wishes more than their own (Davison, 2010; Han et al. 2019). Treatment choices, in this case dialysis or not, need to align with a person's goals and values, with evidence that older patients with advanced kidney disease may prioritise maintaining independence over staying alive (Ramer et al., 2018) and that CKM may be more congruent with their life stage priorities (e.g. Moustakas, Bennett and Tranter, 2015; Seah et al., 2015). However, there is evidence that some nephrologists (kidney specialist doctors) are reluctant to discuss it as they feel it is giving up and not treating the patient (Ladin et al., 2018). However, CKM is treating the illness experience holistically and realistically and to the benefit of QOL, thus not discussing it raises interesting ethical and moral questions (Chan, Parry-Jones and Jackson 2021). For other patients, typically those in end-stage renal disease, kidney transplantation may be an option, but while the physical and survival benefits of transplantation may outweigh dialysis, the psychosocial benefits are less clear. For example, a two-phase qualitative study of 30 transplant patients (14 received a living-donor's kidney; 16 had a deceased donor), which involved interviews with 18 patients, and then focus groups with the remaining 12 patients to pursue the themes emerging from the interviews and triangulate the findings, identified a range of emotions and challenges to adjustment from pre to post-transplantation (Schipper at al., 2014). For example, anxiety and impatience challenged feelings of hope while awaiting donation, and while patients felt grateful for their transplant and to the donor, and while some had faith in their new kidney, others worried it may not last, and yet others struggled with side effects such as fatigue and weight gain. Reporting negative outcomes, such as disillusionment, led to feelings of guilt for not being more grateful. Guilt again appeared where the donor was considered, particularly for those who had deceased donors. There was also guilt for those still awaiting transplants, and guilt about not knowing how best to express one's gratitude to living donors. Guilt is a complex emotion. Problems were also seen in adapting to improvements in health and even a changed life and role outside the 'patient role' that they and their families had become accustomed to. One woman described how 'My husband saw me changing – from being dependent to becoming independent. We had to find a new balance. I wasn't the woman I was before'. For some this also meant a loss of their support systems as they were expected to be able to manage. Adapting to the new situation saw the use of adaptive coping such as positive reappraisal, reprioritisation, benefit-finding (see earlier section), and for some, taking responsibility for one's health and health behaviour, all of which helped to develop resilience. The complexity of emotions seen in these patients, from gratitude to guilt, was tied up with prior expectations and highlights the importance of doctor–patient communications with regards to 'selling' transplantation as a positive option to kidney dialysis. It also highlights a possible need for cognitive-behavioural intervention (see Chapter 17 ☛) in order to manage expectations and any negative emotional consequences of transplantation for patients and their families.

At all stages of treatment, health professional communication is key to whether a patient feels informed, cared for, and able to make choices about their treatment that address their needs and their goals (Brataas et al., 2009). It is not uncommon for needs regarding open, sincere and clear communications to be high on patients' lists of salient needs, although many (but not all) studies do, thankfully, find these needs to have been met satisfactorily (Morrison et al., 2011).

PTSD is a frequent response to highly stressful circumstances, and in particular those in which the individual feels highly threatened in some way and literally feels in fear of their life; in the context of health, this would include the experience of frightening, sudden onset, and unexpected crises such as an MI or pulmonary embolism (see Chapter 8 ☛). A particularly relevant trigger to PTSD at the present time is the experience of being cared for in intensive care units (e.g. Zisopoulos, Roussi and Mouloudi, 2020). Here, people may be sedated and experience significant nightmares that they are unable to reality check due to their reduced level of consciousness and may reexperience these nightmares in the months following recovery from their illness. Not surprisingly, rates of PTSD among hospitalised COVID-19 patients are high even if they were not admitted to intensive care.

Tarsitani et al. (2021), for example, found 10 per cent of COVID patients had clinical levels of PTSD at three months following discharge, while a further 8 per cent had sub-clinical level symptoms.

## Reactions at the end of treatment

In the immediate period following treatment, patients and their families may experience a degree of emotional ambivalence: on the one hand, the treatment and any side effects have stopped, but on the other hand, a sense of vulnerability and of being abandoned can result from decreased contact with the health professional staff, with whom relationships have inevitably built up during treatment. This feeling of 'abandonment' following treatment discharge has been reported in various patient groups, for example, among cancer patients (Costanzo et al., 2007) – it may be that when cancer survivors no longer need to focus so much of their attention on medical treatment, room is left for a psychological struggle to begin (Schnipper, 2001), and at this time some of the support available during treatment recedes, from friends and family, as well as from the health professionals, which can contribute to feelings of distress (Stanton et al., 2005). However, increased distress at this time is not inevitable if patient expectations are managed. For example, Wiles et al.'s (2004) qualitative study of stroke patients' experience found that, where discharge expectations were 'managed well', distress and disappointment was contained to the cessation of physiotherapy rather than disappointment in terms of lost expectations of further potential recovery. In considering conflicting findings of the effect of treatment ending for cancer studies Costanzo suggests that distress specific to worry or anxiety regarding recurrence may increase, where more global negative mood, or depression, may not (Costanzo et al., 2005).

A transition from curative to palliative treatment, if the former is unsuccessful, can be extremely distressing for patients, if they understand this transition. The rates of depression are moderate among people who are dying, ranging in a review of ten years of research, from 12.2 to 26 per cent (Massie, 2004); however, anxiety levels can be higher. The certainty of death commonly brings with it emotional and existential crises and palliative or end-of-life care plays an important role in the quality of life of the dying person (see 'Issues').

## Fatigue

One physical aspect of illness or associated treatments, which is pervasive in many chronic conditions, is that of fatigue: for example, post-viral fatigue, post-stroke fatigue, post-chemotherapy fatigue, post-surgical fatigue. Fatigue is represented by a significant decline in physical and mental performance following an illness event, and is commonly seen in neurological conditions including stroke (prevalence ranging from 36 to 77 per cent). Multiple sclerosis (reported in up to 83 per cent of patients) (Kluger et al., 2013) and over long periods of time following viral infections, for example, over 40 per cent of SARS (Severe Acute Respiratory Syndrome) survivors assessed at four years reported chronic fatigue (Lam et al., 2009). While fatigue is likely due in large part to the relevant neurological, immunological, hormonal and inflammatory processes of the various illnesses, the consequent emotional demands of the symptoms and often of the experience of intrusive treatments are also thought to play a role. We have also seen recorded fatigue cases within our healthcare systems during the COVID-19 pandemic. These are thought to be partly due to the effects of the inflammatory reaction to the underlying virus SARS-Cov-2, a reaction which has been referred to as a 'cytokine storm' (Islam, Cotler and Jason, 2020). (Cytokines are described in Chapters 8 and 11 ☛ as part of the bodies stress response.)

Fatigue can be assessed by evaluating performance such as the speed and strength of physical movement (motor function), or derived from indices of sleep amount and quality, but is also often recorded through subjective reports, such as the Fatigue Assessment Scale (Michielsen et al., 2003). This subjective fatigue has also been explored in those diagnosed with CFS – Chronic Fatigue Syndrome which is characterised by pervasive and persistent fatigue in the absence of any identified pathology. Studies within the CFS population (e.g. Moss-Morris and Chalder, 2003; Wearden et al., 2012) have found associations between fatigue, depression and anxiety, although these associations also exist in populations where an underlying physical condition has been identified, such as cancer (see Brown and Kroenke's review, 2009), lung disease, diabetes, CHD and rheumatoid arthritis (Katon et al., 2007). Such negative emotional correlates of fatigue can increase the detrimental impact of illness on a person's life, and of course any relationship is likely to be bidirectional.

Fatigue is consistently associated with impaired quality of life, with inactivity as a result of fatigue contributing to further weakness: i.e. it can become a 'self-perpetuating cycle where physiological changes, illness beliefs, reduced and inconsistent activity, sleep disturbance, medical uncertainty and lack of guidance interact to maintain symptoms' (Moss-Morris et al., 2013: 303). In addition, as described in the next chapter, the responses of significant others to a loved one's illness, or in this case, persistent fatigue, may influence other patient outcomes (Band et al. 2015).

### The effect of negative emotional reactions to illness

Depressed people are less likely than non-depressed people to engage in illness self-management, for example, to adhere to medication (Lin et al., 2004), cease smoking following a heart attack (Doyle et al., 2014), or engage in cardiac or orthopaedic rehabilitation exercise (Lane et al., 2001; Pomp et al., 2012). The effect of depressed mood may also extend to risk-taking. For example, depressed HIV-positive homosexual males reported twice the rate of engagement in unprotected anal sex with partners than did non-depressed men (Rogers et al., 2003).

Although less often studied than depression, anxiety is also associated with poorer illness self-management: for example, control of blood glucose levels among those with diabetes (e.g. Niemcryk et al., 1990), and poorer response to haematological cancer treatments in those undergoing stem cell transplants (e.g. Park et al., 2010). Evidence for an influence on disease course has also been reported: for example, the experience of distressing events preceded exacerbation of symptoms and relapse in those with multiple sclerosis (Ackerman et al., 2002).

Depression also exerts a significant influence on whether such patients resume pre-illness functioning, particularly in terms of return to work and social activities. This could be due to the symptom inflation commonly witnessed among depressed people, or to reduced expectancies of positive outcomes leading to disengagement (Bjärehaed et al., 2010; Pomp et al., 2012) (see Chapter 9 ☛). There is consistent evidence that depressive illness is a significant cause of morbidity and disability and even mortality, for example, following a stroke (see review of 28 prospective studies conducted by Pan et al., 2011) or those with heart failure (Gathright et al., 2017). Furthermore, a meta-analysis of 17 studies of the impact of emotional wellbeing (primarily measures of positive affect as indicated by depression or mood scores) found significant effects on recovery and survival among individuals with a range of physical conditions. This led the authors to conclude that positive emotional wellbeing has prognostic significance, albeit small, for the recovery and survival of those with physical illness (Lamers et al., 2012).

Emotion regulation is important to illness outcomes. In other words, how a person experiences, processes and copes with their emotions can impact on their adjustment, with avoidance and repression of one's emotions generally maladaptive, and acknowledgement and expression of how one feels, generally adaptive (see review by de Ridder et al., 2008). Although positive emotions were not assessed explicitly in this review, the results point to a growing area of research, which we therefore turn to next.

## Positive responses to illness

There is consistent evidence that positive dispositional characteristics and positive appraisals can influence illness outcomes either directly or indirectly, and even that illness itself can bring about positive changes.

### Positive appraisals and positive emotions

Having a positive or optimistic outlook has been consistently associated either directly or indirectly (via effects on coping responses) with positive outcomes (see also Chapter 12 ☛). Among adults aged 85 years and older, where you may expect physical factors to be dominant, optimism was significantly associated with the likelihood of survival over a five-year period (Jacobs, Maaravi and Stessman, 2021). Being optimistic and having higher mastery beliefs was associated with less severe pain and reduced fatigue among cancer patients followed up over ten weeks from receiving chemotherapy (Kurtz et al., 2008). Conversely, pessimists endorsed more maladaptive coping strategies, which predicted emotional morbidity, among the post-surgical breast cancer patients assessed by Schou and colleagues (Schou et al., 2004).

Fredrickson (1998, 2001) summarised the key benefits of maintaining positive emotions as:

- the promotion of psychological resilience and more effective problem solving;
- the dispelling of negative emotions;
- the triggering of an upward spiral of positive feelings.

Illustrating these benefits, Fredman and colleagues (Fredman et al., 2006) reported that elderly hip fracture patients who had high levels of positive affect during initial hospitalisation had better functional recovery as seen in their standing and walking speeds at 2-, 6-, 12-, 18- and 24-month follow-up, than those with initial low levels of positive affect. Those with consistently high levels, i.e. high positive affect at each time point, had the best functional recovery.

Why might such effects of positive appraisals and positive emotions exist? It is thought that such factors may have beneficial effects on the immune function and a person's inflammatory responses (Dockray and Steptoe, 2010; Rasmussen, Scheier and Greenhouse, 2009), as also discussed in the chapter on moderators of the stress experience (Chapter 12 ☛). However, maintaining positive emotions form only part of a person's response to illness: the coping strategies that a person adopts to help them to cope with the disease and its consequences are also important in determining illness outcomes as we describe below (see also Chapters 9, 11 and 12 ☛ for a discussion of Leventhal's self-regulation model of illness and Lazarus's stress-coping theory).

## Coping with illness

Moos and Schaefer (1984) described the experience of illness as a 'crisis' (crisis theory), whereby individuals face potential changes in identity (healthy person to sick person, for example), location (home to hospital or nursing home), role (e.g. independent to dependent), and changes to aspects of social support (e.g. from socially integrated to socially isolated). The coping strategies used to cope with illness do not differ from those used to cope with any other problem that an individual faces: in other words, illness does not trigger unique coping strategies, and, as such, the theory and concepts of coping outlined in Chapter 11 ☛ are as relevant here as they are to consideration of stress coping. However, as with stress, there needs to be a distinction between acute illness events (e.g. flu, minor surgery) and chronic illnesses, as these present the individual with a different set of challenges. The accepted 'cut-off' for becoming 'chronic' tends to be where an illness and its symptoms or effects last for greater than six months, or where there may be no potential for cure. Some, but not all, chronic diseases are progressive, for example asthma is not, whereas many forms of cancer or arthritis are.

Moos and Schaefer (1984) identified three processes that resulted from the crisis of illness:

1. *Cognitive appraisal:* the individual appraises the implications of the illness for their lives.
2. *Adaptive tasks:* the individual is required to perform illness-specific tasks such as dealing with symptoms, and general tasks such as preserving emotional balance, or relationships with others (see below).
3. *Coping skills:* the individual engages in coping strategies defined as either appraisal-focused (e.g. denial or minimising, positive reappraisal, mental preparation/planning); problem-focused (e.g. information and support-seeking, taking direct action to deal with a problem, identifying alternative goals and rewards); and emotion-focused (e.g. mood regulation, emotional discharge such as venting anger, or passive and resigned acceptance).

Full discussion of cognitive appraisals of stress and illness can be found in Chapters 9 and 11 ☛. Here we explore further Moos and Schaefer's second and third processes. The adaptive tasks required as a result of chronic illness include:

- dealing with the symptoms of the disease and the possibility of pain;
- maintaining control over illness, including aspects of symptom management, treatment, or prevention of progression;
- managing communicative relationships with health professionals;
- facing and preparing for an uncertain future;
- preserving self-image and possibly self-esteem when challenged (e.g. by altered appearance or function);

- maintaining control and emotional balance over health and life in general;
- dealing with changes in relationships with family and friends.

These challenges are generic to many different conditions, although aspects may vary in strength and salience depending on the condition: for example, dealing with treatments may present greater challenges to adaptation in those with painful arthritis than among those with asthma. Age may also bring unique challenges as reported in a study of adolescents with type 1 diabetes where being 'bugged' by parents about diabetes self-care was the second highest diabetes-related stressor (Jaser et al., 2017). How a person chooses to deal (cope) with these challenges may vary, as we shall describe below (and see also Chapters 11 and 12 ☛).

## Coping by denial or avoidance

A common initial response to diagnosis or illness onset is either conscious or unconscious denial of its occurrence, or subsequently ignoring or. disengaging from the problem. Avoidant coping tends to follow where a person appraises the stressor, for example in the context of cancer, as harmful or as posing a loss (Franks and Roesch, 2006), however, in the longer term denial and avoidance tend to interfere with active coping efforts and are associated with increased distress (Stanton et al., 2007). Typically studies report negative outcomes of avoidant coping and denial – for example:

- Avoidant coping and emotion-focused strategies were associated with greater depression than problem-focused coping among a sample of HIV-positive homosexual men (Safren et al., 2002).
- In a meta-analysis of studies of coping among men with prostate cancer, avoidant coping was generally associated with maladjustment (Roesch et al., 2005), likewise in a systematic review of coping among men and women with a head and neck cancer, disengaging or avoidant coping had a moderate-to-large association with psychological distress (Morris et al., 2018).
- Cognitive avoidance coping, including passive acceptance and resignation, among women with breast cancer was associated with a significant risk of poor long-term psychological adjustment at a three-year follow-up (Hack and Degner, 2004).
- Among a study of adolescents with Type I diabetes, disengaging and avoiding coping strategies were predictive of poorer Qol and more depressive symptoms over 12 months, compared to problem-solving and engagement coping, although no form of coping was associated with glycemic control (Jaser et al., 2017).

A recent review found that 79 of 98 articles reviewed (80.6 per cent of studies included) demonstrated a positive association between avoidant coping and poorer psychosocial adaptation in a range of health conditions, although the authors advise caution in over concluding from this given the diversity of study samples, study designs (over reliance on cross-sectional designs) and the conceptualisation and measurement of coping, often using generic rather than illness specific coping measures (Livney, 2019). Notably also some studies find avoidant coping to operate independently of a range of psychosocial outcomes, for example as found in a study of lower limb amputees (Pereira et al., 2018).

## Problem-focused and acceptance coping

Generally speaking, after the initial period following illness onset or diagnosis has passed, problem-focused coping, such as making use of social support resources or planning how to deal with the problems faced, and acceptance coping are associated with more positive adaptation (Stanton et al., 2007). Among an adolescent sample, living with type I diabetes, what was described as primary control engagement coping (i.e. problem-solving, emotional modulation, emotional expression)) or secondary control engagement coping (i.e. positive thinking, cognitive restructuring, acceptance, distraction) predicted fewer depressive symptoms and QoL problems than disengaged or avoidant coping (Jaser et al., 2017). Among adults Lowe et al. (2000) found that acceptance-focused coping (e.g. accepting things as they are, reinterpreting things in a positive light) was the most prevalent form of coping in hospital and at a six-month follow-up, was associated with lower levels of distress. In addition, problem-focused coping was associated with high levels of positive mood, and emotion-focused coping was associated with low mood.

People engage in all sorts of coping efforts and, as described in Chapter 11 ☛, do not generally use strategies defined as only emotion-focused, only problem-focused or only avoidant. This is because situations including most illnesses are generally dynamic and multidimensional, and therefore responses also need to be dynamic and multidimensional. As evidence of this, a study of young people within two months of developing cancer (Kyngaes et al., 2001) found that emotion-focused, appraisal-focused and problem-focused strategies were all employed, with the most frequently used being accessing social support (seeking information from health professionals as well as emotional support from families), believing in recovery, and returning to 'normal' life (positive reframing). Some authors point to a 'time *X* strategy interaction' whereby different strategies are adopted at different periods in the illness 'crisis'. This shift may be highly functional. Stanton et al. (2002a) reported a complex relationship between positive future expectancies, coping and outcomes of women with early-stage breast cancer. Active acceptance at the time of diagnosis predicted better adjustment in terms of mood and reduced fear of recurrence than did avoidant strategies. Pessimism about the future was associated with coping by turning to religion, whereas those women who retained high amounts of hope for the future generally benefited from the use of more active coping strategies.

## Religious coping and spirituality

Ethnic and cultural variations have been found in the extent to which individuals are actively religious (religiosity/religious beliefs). That the nature of coping responses to illness can be influenced by culture, was suggested by Roy et al. (2005) when their study of an ethnically diverse British cancer population revealed that UK Asians who were more depressed than the Caucasian sample endorsed helplessness and hopelessness and a greater fatalistic attitude to coping. Differences have also been shown in the extent to which Europeans, Americans, Asians, Africans and Latinas use religious-based coping, with religious beliefs and spirituality also being a component of quality of life for some more than others (e.g. Culver et al., 2004).

Religious beliefs have been associated with higher perceived challenge appraisals, greater optimism, hope, meaning-making (positive appraisals of events, personal growth (cf. V. Lee et al., 2006b)), and better emotional and physical adjustment in older adults' response to general stress (Park, 2006). In a study of 793 elderly adults attending a diabetes care centre, the influence of religiosity on both medication adherence and health-related QoL was mediated by religious coping, and by social support (Saffari et al., 2019). Religious beliefs are reflected in coping behaviours across a range of other age groups and illnesses (e.g. breast cancer, Gall et al., 2000; rheumatoid arthritis, van de Creek et al., 2007; cardiac surgery patients, Ai et al., 2004), although the benefits are not consistently reported. This may be in part due to measurement differences, although most studies distinguish cognitive and behavioural religious coping (RC) strategies and their functions, with some further distinguishing positive or supportive RC where God is seen as 'supportive' and comforting, negative RC where a less secure relationship exists with a more distant and 'punishing' God, and between active and passive RC. (e.g. Pargament et al., 2000; Loewenthal, 2007). Loewenthal (2007) described how a belief in a 'punishing' God was associated with poorer mental health than beliefs in a benign 'supportive' God. Where religious coping may often be considered passive, it is not necessarily so: consider, for example, attending prayer groups as a form of seeking support from like-minded others, or of setting out to help others (Harrison et al., 2001), both could be considered as active coping. A review of 17 studies (Thuné-Boyle et al., 2006) concerning adjustment to cancer found that religious coping benefited distress and adjustment in seven studies (three found benefits only for specific sub-groups according to race, extent of 'hope'), seven studies found no beneficial effects, and three studies in fact found religious coping to be harmful.

In the Western world many people will describe themselves as spiritual, but not religious (Csof et al., 2009) and, although empirical evidence is typically sought in psychological science, interest in human spirituality has grown (Collicutt, 2011). Spirituality can be contrasted with religion in that it tends to be more personal and individualistic rather than institutional or collectivist; more emotion-focused than problem-focused; directed inwards more than outwards; more concerned with self-actualisation than sacrificial demands or duties, and more

**Photo 14.1** Buddhist monks at a meditation

*Source*: Suti Stock Photo/Shutterstock.

anti-authoritarian than religion (e.g. Koenig et al., 2001). Many of the third-generation therapies have a ‘spiritual’ element, for example mindfulness-based practice and meditation (see Chapter 16 ☛). It appears likely that religiosity or also spirituality affect illness experience by influencing appraisals of meaning, by maintaining hope, or by influencing coping, although there remains a need for further research into the role such beliefs play in illness outcomes.

# Illness outcomes

## Finding benefit and post-traumatic growth

There are increasing reports that those facing significant health or life stressors often report gains from their experience – this is not a new phenomenon but more a reflection of a shift in research attention. Commonly referred to as benefit-finding, studies of this phenomenon fit within a larger framework described as **‘post-traumatic growth’**, whereby individuals experience positive psychological change as a result of a struggle with stressful life circumstance(s) (Tedeschi and Calhoun, 2004; and see the handbook of Calhoun and Tedeschi 2007 for a discussion of post-traumatic growth following a range of stressors).

Five domains of positive change as a result of stress or trauma have generally been identified:

1. enhanced personal relationships;
2. greater appreciation for life;
3. a sense of increased personal strength;
4. greater spirituality;
5. a valued change in life priorities and goals.

In an early study, Petrie et al. (1999) found that 60 per cent of those who had had a heart attack or had developed

post-traumatic growth

following a traumatic event, including serious illness, a person may experience positive psychological change, e.g. increased life appreciation, improved relations to self and others, new life values and priorities breast cancer reported some personal gains over the first three months following illness onset, and 58 per cent reported specific positive effects of their illness (see Figure 14.1). The most commonly endorsed benefits were improved close relationships, increased empathy among women with breast cancer, and a healthier lifestyle for men following a heart attack. Also within a cancer population PTG predicted lower cancer-specific stress at 12 months, and lower generic stress at 18 months (Groarke et al., 2015) and was seen to include factors representing perspective shifts and finding meaning, such as an improved appreciation of life or relationships, a deepened spirituality, a sense of personal strength or future potential. Improved relationships with significant others is commonly reported among those with other conditions (e.g. rheumatoid arthritis, Danoff-Burg and Revenson, 2005).

The strength of these possible dimensions of growth varies across studies depending on the event and sample under consideration, but there is reasonable consistency as to their presence from quantitative studies including reviews (e.g. Helgesen et al., 2006 – health problems, life events, trauma; caregiving; Shand et al., 2015 – review in cancer patients; Groarke et al., 2015 – breast cancer; Danoff-Burg and Revenson, 2005 – rheumatoid arthritis) and from qualitative studies (e.g. Gall and Cornblatt, 2002 – cancer; Parveen and Morrison, 2012 – caregiving). Barskova and Osterreich (2009), in their review of PTG across a range of health conditions (cancer, HIV/AIDS, rheumatoid arthritis, multiple sclerosis and cardiac disease), conclude that there is potential adaptative significance to PTG in relation to a range of health outcomes, however findings are often specific to patient groups. This was also reported previously by Tomich and Helgeson (2004) who found a subgroup of women for whom benefit-finding was associated with higher distress over time – those with advanced disease. They suggest that benefit-finding may have reflected early unrealistic hope which, when unmatched by outcomes, became a cause of distress. This points to the importance of realism. In further evidence of the influence of stressor type on whether benefit finding is adaptive, Helgeson and colleagues' review of cross-sectional studies (as too few longitudinal studies were available at the time to conduct a meta-analysis on) found that benefit-finding was associated with less distress in those experiencing a health/illness stressor as opposed to other life stressors. Curiously, benefit-finding also related to one interpretation

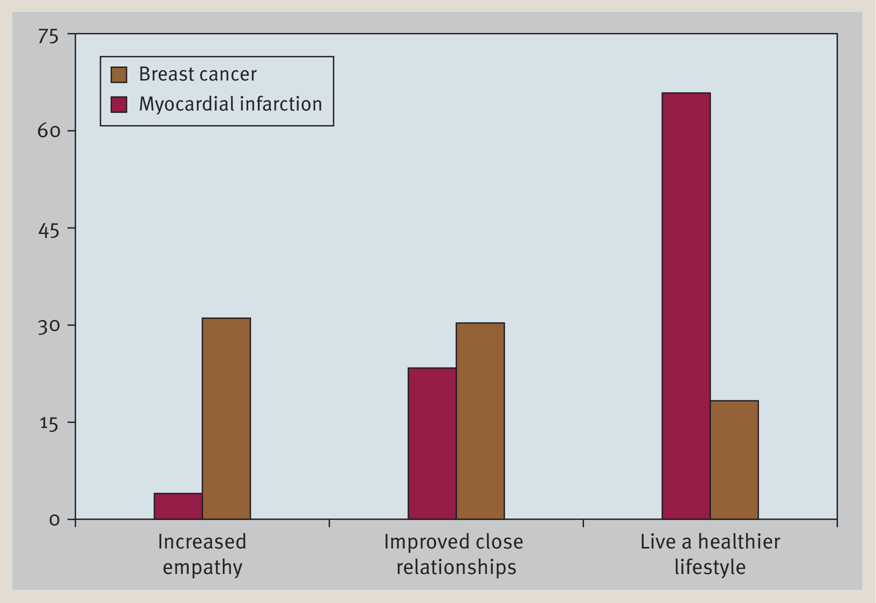


**Figure 14.1** Gains can be similar or different according to health condition (examples from Petrie et al, 1999)

*Source*: Petrie et al. (1999).

is that this cognitive processing, even rumination, is a necessary cognitive process for benefit-finding or growth to be achieved. There is in fact supportive longitudinal evidence that the development of PTG may be facilitated by facing early struggle with the illness, as seen in a study with breast cancer patients where those with higher initial cancer specific stress and anxiety exhibited greater PTG over an 18month period (Groarke et al., 2015).

Benefit-finding has been identified as a potential predictor of outcomes, such as improved mood, better adjustment or QoL. For example, it has been suggested that good relationships between couples may work towards the creation and maintenance of positive emotions (in patients and/or caregivers), which may benefit adjustment (de Vellis et al., 2003). Becoming more accepting of things in life or having closer relationships with family or friends may in fact lead to reported QoL levels higher than those reported by healthy individuals (as reported by Tempelaar et al., 1989, cited in Schulz and Mohamed, 2004).

Benefit-finding has also been considered by some as an outcome in its own right. In these instances, as with predicting negative consequences of illness, personal characteristics and psychosocial resources, including coping responses, are potential influences. Stanton et al. (2007) and de Ridder et al. (2008) in their reviews note that younger age is commonly associated with benefit-finding, minority ethnic status and lower socio-economic status have variable effects and gender tends not to exert a significant effect. So what other factors might influence the experience of benefits or growth? A prospective study of 105 cancer patients, interviewed at one, six and twelve months following tumour surgery found that finding benefit at twelve months was directly predicted by levels of self-efficacy (a personal resource) and social resources (amount of social support received) at one month (Schulz and Mohamed, 2004). However, as can be seen in Figure 14.2 (in which the arrowed lines with asterisks reflect significant associations), when examining whether coping mediated the relationship between such personal and external resources and benefit-finding, individuals with high social support resources exhibited greater benefit-finding regardless of whether **acceptance coping** or **social comparison** coping was used, whereas the beneficial effect of self-efficacy appeared to be mediated by coping (as the direct association between self-efficacy and finding benefit was insignificant).

**acceptance coping**
accepting the reality of a situation and that it cannot easily be changed

**social comparison**
the process by which a person or group of people compare themselves (their behaviour or characteristics) with others

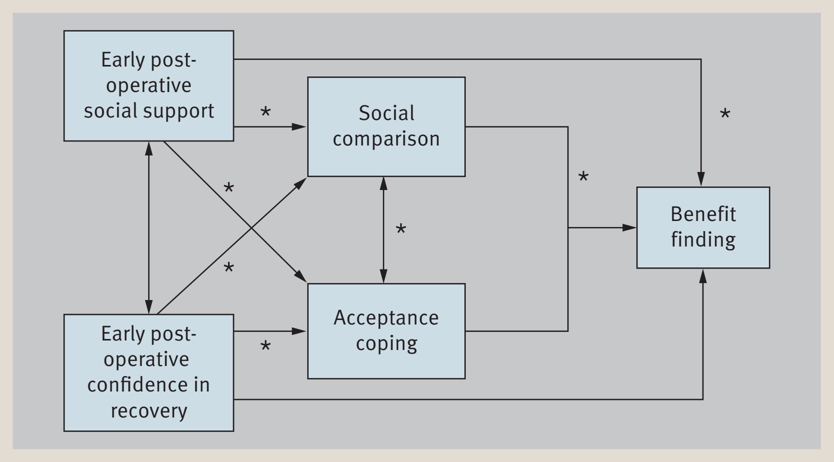


**Figure 14.2** The direct and indirect effects of internal and external resources upon benefit finding

*Source*: Adapted from Schulz and Mohamed (2004: 659).

These are important prospective findings, because assessing such variables retrospectively (as many studies have done) runs the risk of, as Stanton et al. (2007) point out, the time since the event influencing the extent to which growth is reported. People may reconstruct their past experiences in order to make them more congruent with current experience. Benefit-finding, or the reporting of gains (see Chapter 15 ☛ on caregivers) could therefore be considered a form of coping. Optimism is also a factor that influences reported benefit, indeed optimism was strongly associated with PTG in Shand's (Shand et al., 2015) review of 116 studies conducted with cancer patients. Optimists tend to reappraise events in positive ways, and also tend to cope in a more problem-focused way. In addition, searching for 'meaning' via finding a sense of order or purpose in one's new situation is a form of cognitive restructuring that may help a person deal with or adapt to the challenge of illness (Sharpe and Curran 2006; Park, 2010).

Benefit-finding and 'post-traumatic growth' may be an integral part of 'normal' life experience. To address this, Park and Lechner (2007) note the importance of including control groups in research studies – this is not as common as it should perhaps be.

Also, what is the relationship between the experience of post-traumatic symptoms (PTS) and post-traumatic growth (PTG)? Is the experience of stress necessary for the experience of growth and are they on a continuum? A systematic review and meta-analysis of data from 116 studies conducted with cancer patients reported that PTG only had a modest association with post-traumatic stress symptoms, and that there were different psychosocial corelates of each (Shand et al., 2015). PTS were strongly associated with depression, anxiety, global distress and low physical QoL and social support, whereas PTG was strongly associated with positive reappraisal, religious coping, spirituality, optimism, social support and less so with age, gender, low distress and depression. This suggests that PTS and PTG are not simply at the opposite ends of a response to illness continuum although as yet few studies have in fact explored the role of positive factors such as optimism in the experience of PTS, and many studies also are correlational and not prospective and so the nature of the relationship between PTS and PTG, and the influence on it, are yet to be fully understood.

The final point worth considering here is that cultural variations may exist in the nature of personal growth or benefit-finding. Ho et al. (2004) suggest that individuals from Asian cultures which are more 'collectivist' in approach to health and illness (see Chapters 1 and 9 ☛) may not make changes to their personal outlook, goals or priorities to the same extent as individuals from more 'individualistic' cultures. We return to this issue in the next chapter with regards to reported caregiver gains (Chapter 15 ☛).

## Illness acceptance

Part of the process of adjusting to illness is the individual process of evaluating its impact on their lives and that of those around them, and a central part of this is thought to be the extent to which the person 'accepts' their illness. Acceptance of illness has been defined as 'recognizing the need to adapt to chronic illness while perceiving the ability to tolerate the unpredictable, uncontrollable nature of the disease and handle its adverse consequences' (Evers et al., 2001: 1027, as cited in Casier et al., 2013). This is not to suggest passivity, but rather, acceptance is considered as beneficial to both patient mood and coping and and is associated with a continued engagement in life goals other than illness-related ones. Acceptance has been associated with a range of key health outcomes, for example reduced pain-related disability (McCracken and Eccleston, 2003), enhanced wellbeing, such as that found among adolescents with cystic fibrosis (CF) (Casier et al., 2011, 2013) or satisfaction with life as seen among those with multiple sclerosis (Pakenham and Fleming, 2011).

Generally, acceptance is considered to be necessary if a patient is to 'move on' with their treatment or with their life more broadly. This is reflected for example in the wording of items within the Acceptance of Chronic Health Conditions Scale (Stuifbergen et al., 2008), for example, as adapted for a study of those with multiple sclerosis (Wright and Kiropoulos, 2017), 'I can't conquer MS but I can adapt to it', or 'I think of MS as just part of who I am'. In a study of cardiac patients who had experienced heart failure, for example (Obieglo et al., 2015), those with lower illness acceptance were more likely to report less energy, more severe pain, negative emotional reactions, sleep disorders and limited mobility, and were socially isolated. This wide-ranging effect on indices of quality of life have led to suggestions of acceptance-enhancing interventions (Chapter 16 ☛).

Acceptance of one's illness or condition may be challenged where there is a high degree of visibility: for example, in burns or injury victims, those born with congenital disfigurement or those left with post surgical scarring (Rumsey and Harcourt, 2005; Harcourt, 2017; and see 'Research focus').

# Quality of life

While the primary goal of medicine and healthcare is to treat and cure illness and its symptoms in order to reduce morbidity and premature mortality, using typically what are termed 'objective health indicators' such as observing improved physical functioning, reduced symptomatology, there is a need to address more global outcomes of healthcare treatments and services including patient satisfaction and wellbeing. These subjective outcomes require that the view of the patient and or their families, are sought. For example, in a clinical trials to test the efficacy of a new drug or an intervention study based on either psychological principles such as CBT, it is important to evaluate not only clinical outcomes but also the individual's perceptions of how the treatment or intervention has influenced their illness experience and general psychosocial functioning. As noted in Chapter 1 ☛, people are living longer, often with some dependency needs or with some aspect of their life restricted, and as a result, there has been a significant growth in quality of life (QoL) research, addressing Boini et al.'s (2004: 4) observation that 'physicians now have the opportunity to add life to years, as well as adding years to life'. As noted in Chapter 1 ☛, and as recognised by the World Health Organization, health is defined in terms of 'physical, mental and social wellbeing, and not merely the absence of disease and infirmity' (WHO, 1958, p. 459). We have seen the emergence of two fields of research, one which addresses wellbeing, and one which addresses QoL, with many overlaps as will be described below.

## What is quality of life?

Early QoL seen in surveys in the 1970s, incorporated measures of life satisfaction, wellbeing, affect and life stress, but from 1991 when the WHO adopted the term with a view to developing a global measure, the definition broadened. According to the World Health Organization Quality of Life (WHOQOL) working group (1993, 1994), QoL is a person's perceptions of their position in life in relation to their cultural context and the value systems of that context in relation to their own goals, standards and expectations. Quality of life is a broad concept affected by an individual's physical and mental health, level of independence, quality of social relationships, social integration and, added subsequently (WHOQOL 1998), their personal, religious and spiritual beliefs. This working group produced the generic and cross culturally valid assessment tool (WHOQOL-100), which addresses 25 different facets of QoL grouped into one of six domains:

1. *physical health:* pain and discomfort; energy and fatigue; sleep and rest;
2. *psychological:* positive feelings; self-esteem; thinking, memory, learning and concentration; bodily image and appearance; negative feelings;
3. *level of independence:* activities of daily living (e.g. self-care); mobility; medication and treatment dependence; work capacity;
4. *social relationships:* personal relationships; practical social support; sexual activity;
5. *relation to environment:* physical safety and security; financial resources; home environment; availability and quality of health/social care; learning opportunities; leisure participation and opportunities; transport; physical environment;
6. spirituality, religion and personal beliefs.

This generic tool provides core items for use across all conditions, with disease- and population-specific versions being developed subsequently (see later). Most of the available QoL measures are composite scales which address the multiple dimensions described above, which seems to hold face validity – in other words if you asked someone what their 'quality of life' was, their answer would likely reflect many differing aspects of their life.

However, early studies tended to focus more keenly on physical function as if QoL was reflected fundamentally in what a person could 'do', and thus studies typically measure disease or symptom severity, disability or physical functioning as outcome measures considered to be indicative of quality of life. However, the WHO model of impairment, disability and handicap (see Chapter 1 ☛) (WHO, 1980) described how illness had more than just physical consequences, because handicap was defined as disadvantages and limitations in performing social roles that resulted directly from impairment and/or disability. However, as we have shown throughout this psychology text the linear relationship between impairment, disability and handicap, or, as defined in the WHO's revised model (International Classification of Functioning, Disability and Health, WHO, 2001), between impairment, activity limitations and participation restrictions, is not inevitable but depends on many psychological and social factors. Support for this is seen, for example, among individuals suffering from rheumatoid arthritis, where the link between pathophysiology and disability outcomes is often indirect and moderated by psychosocial and environmental factors (see Walker et al., 2004, for a review), or in stroke patients receiving a workbook intervention targeting their beliefs in control over their recovery, where disability was reduced relative to a control group (Johnston et al., 2007). Rather than considering disease or disability as indicative *of* quality of life, they could therefore be considered as potential influences *upon* it (McKenna et al., 2000; McKenna, 2004) that may or may not affect a person's perceived QoL, depending on the extent to which that individual rates them as important to that judgement (e.g. Cox, 2003).

In general terms therefore, quality of life (QoL) can be referred to as an individual's evaluation of their overall life experience (their situation, experiences, states and perceptions) at a given time (global quality of life). The term 'health-related QoL' (HRQoL) emerged to refer to evaluations of this life experience and how it is affected by symptoms, disease, accidents or treatments, and also by health policy. It should also include some assessment of the patient's level of satisfaction with treatment, outcome and health status and with future prospects' (Bowling, 1995a: 3).

## Wellbeing vs QoL?

Note that in Bowling's definition of HRQoL presented earlier, that 'wellbeing' is contained within the definition. Wellbeing has historically been presented as a broader construct, encompassing social and economic wellbeing, which can be objectively determined at a national and individual level (e.g. from economic, employment, living arrangements and health indices) as well as psychological wellbeing or personal wellbeing which are typically self-reported.

Within the health and social sciences, wellbeing has been approached in two ways, firstly as a person's affective judgment of their happiness relative to their ideal/their aspirations i.e. subjective wellbeing seen in the presence of positive affect and a lack of negative affect (Diener, 2000; Diener et al, 2009). This has been described as **'hedonic'** i.e. wellbeing achieved through pleasure and in being satisfied with achieving one's goals. In contrast a more **'eudaimonic'** perspective addresses wellbeing derived from personal growth, self-actualisation and values and is thought to come from being engaged and contributing-not just receiving (e.g. Ryff, 1989). Both are represented in some existing measures of wellbeing such as the Life Satisfaction Index, or Ryff's scales which address self-acceptance, positive relations with thers, autonomy, environmental mastery, purpose in life, and personal growth, while others focus only on subjective, hedonic wellbeing (see McDowell, 2010 for a review of measures).

Some studies have examined the relationship between HRQoL dimensions and subjective wellbeing, and not surprisingly subjective wellbeing is strongly associated with the mental health domains of QoL measures, but not with the physical domains (e,g. Mukuria and Brazer, 2013). Furthermore in an interesting exploratory study examining the relationship between HRQol and SWB over time, breast cancer patients appear to shift towards weighting the social domain of QoL within their SWB, suggesting possible reprioritisation or adaptation (Tessier et al., 2017). Such prospective studies of these interactions during the course of illness are fascinating and challenge the assumption that we always value the same aspects of our health and wellbeing in the same way (see also the later discussion of age).

## What influences quality of life?

For some individuals, the inability to perform valued activities as a result of impairment or disability may be considered a 'fate worse than death' (e.g. Ditto et al., 1996); however, for others they will continue to find

**hedonic**

the goal of living is to maximise happiness and pleasure and minimise negative affect, with a focus on subjective wellbeing and life satisfaction

**eudaemonic**

the goal of life should be to live as one's true self, to strive for meaning, personal growth and self-actualisation, with a focus on psychological wellbeing meaning and purpose in life in spite of disablement (e.g. life-threatening disease such as cancer or HIV infection; Tsarenko and Polonsky, 2011). As noted by Carr et al. (2001), 'health-related quality of life is the gap between our expectations of health and our experience of it' (p. 1240), yet 'existing measures of quality of life do not account for expectations of health'. Not everyone expects good health, and thus poor health may not be judged as impacting on their QoL, and vice versa, with illness considered more damaging to QoL in those who expect good health. 'What do you think?' (below) raises the question of patient preferences in healthcare and in making quality-of-life judgements and introduces the reader to one approach taken by health economists.

## WHAT DO YOU THINK?

Are different health outcomes important to different people? For most people, the choice between a treatment without major side effects and a treatment with major side effects would be an easy decision, i.e. that without the side effects. However, the decision becomes more complex if the choice is now between a treatment without major side effects but with only moderate proven success in eradicating or controlling the illness concerned, and a treatment with significant side effects but with excellent success rates. Which would you choose? These types of decision are faced daily by many cancer patients, who are fighting for survival but facing often toxic treatments in terms of their side effects. The quantity of life may be added to by these treatments, but what about life quality?

If economics also enters the debate, as it increasingly does in terms of treatment costs, costs of hospital stays, costs of follow-up care, etc., then decisions about which treatment outcomes are best often fall into the hands of doctors and hospital managers who are responsible for the spending. The outcome of mortality has little healthcare cost, whereas prolonged life does moreso if it is accompanied by chronic illness or morbidity. Treatment efficacy is central to these decisions with the ideal outcome from a medical standpoint likely to be optimal functioning of the patient, but with decisions generally made by weighing up the costs of treatment (e.g. financial costs, costs to the person in terms of side effects) against the objective benefits (e.g. financial savings from reduced need for further treatment, projected quantity of life gain for the individual).

Health economists increasingly work alongside health psychologists to examine the factors that affect the utility (or as we would say in health psychology, the importance) attached to health states, and how such decisions make patients feel. For example, if you were indifferent as to whether you lived in poor health for six months or in optimal health for three months with treatment, then this would indicate the utility of that treatment for you personally. Basically, these kinds of judgement require individuals to consider how much time in terms of current QoL they would be willing to trade for QoL following treatment: for example, how many days of treatment would you willingly trade for how many months of improved health?

How easy is it to make these judgements in your view and is it fair to ask? What is valued may change over the lifespan. For example, will a 75-year-old cancer patient consider the treatment option of six three-weekly doses of chemotherapy, it's anticipated benefits in terms of extended lifespan, and likely side effects (nausea, achey limbs, hair loss, etc.) in the same way as a 35–40-year-old? It is important to assess individuals' perceptions of what makes *their* life 'quality'.

Many factors influence QoL including:

- demographics: e.g. age, culture;
- the health condition: e.g. symptoms, presence or absence of pain, functional disability; neurological damage with associated motor, emotional or cognitive impairment, sensory or communicative impairment;
- treatment: e.g. its availability, nature, extent, toxicity, side effects, etc.;
- psychosocial factors: e.g. emotions (anxiety, depression), coping, social context, goals and support.

## Age and quality of life

Age has been shown to influence the aspects of life considered to be important to people, and age also will influence the aspects of life that illness has the potential to impact on. For example, cancer treatments commonly impact upon school attendance and participation in school activities important to a child's social development (Eiser, 2004); childhood epilepsy can impede social functioning, independence and relationships with peers as well as, in some cases, self-esteem and mood (McEwan et al., 2004).

In terms of children, it is necessary to understand the different contexts which may mediate the impact of illness and its treatments on the child (Matza et al., 2004), as any effects of impaired QoL in childhood may be cumulative and affect later development (Jirojanakul et al. 2003). Do children with chronic disease modify their future life expectations as a result of QoL being compromised in their childhood? We simply do not know this for sure. Logically, however, we might expect so, given evidence that negative experiences such as social rejection in childhood (a possible consequence of the non-participation some physical illnesses or disabilities may create) can have long-term effects (Maddern et al., 2006). In terms of adolescents, often considered to be a particularly challenging time to be diagnosed with a chronic or serious illness, the evidence is mixed regarding whether or not illness such as cancer has long-term effects on quality of life. For example, Larsson et al. (2010) conducted a longitudinal study of 61 individuals diagnosed with cancer in adolescence (mean age 15.5), and compared their QoL over four years with age- and gender-matched controls. While initially (up to six months post diagnosis), the cancer group had significantly lower mental health and vitality and greater depression than controls, at 18 and 48 months this was reversed and the cancer group actually reported greater vitality and lower anxiety and depression. Such findings fit with research described previously in adult populations, whereby traumatic experience of illness and its associated treatments led to a maturation and heightened appreciation of life, sometimes referred to as post-traumatic growth (Tedeschi and Calhoun, 2004).

While many studies with younger children have relied on parental ‘proxy’ reports of their child’s QoL (see the section on measuring quality of life, below), several interesting studies using **qualitative methods** to elicit domains of importance in QoL and factors that influence it have identified a broad range of influences on quality of life. For example, focus-group discussions among adolescents (aged 11–17) with epilepsy (Cramer et al., 1999, cited in McEwan et al., 2004) identified eight subscales related to health-related QoL:

1. general epilepsy impact;
2. memory/concentration problems;
3. attitudes towards epilepsy;
4. physical functioning;
5. stigma;
6. social support;
7. school behaviour;
8. general health perceptions.

Quantitative results from the same study found that seizure severity was the main predictor of health-related quality of life, independent of age of onset of the illness. In other words, the length of time that the child had had the illness did not reduce the impact of severe seizures on their QoL. In another focus-group study that examined health-related QoL and its relation to distress among younger children (aged 6–12) with epilepsy, distress was mainly associated with loss of independence and restrictions in daily activities, concern about the reactions of others to their illness and seizures, treatment by peers, and concerns about the side effects of medication (Ronen et al., 1999, as cited in McEwan et al. 2004).

The effect of age on QoL ratings is not inevitable. For example, age was not predictive of quality of life in a one-year longitudinal study of stroke survivors ranging from 32 to 90 years old, where other factors, such as physical disability, depressed mood and gender (females had poorer QoL) were (Carod-Artal et al., 2000). It may be that age is less important than ‘life stage’: i.e. the impact of a disabling illness on QoL might vary according to whether or not it occurs at a time in life when a person is still professionally or reproductively active. Among younger people who have suffered an acute stroke, being unable to return to work has been associated with reduced life satisfaction and subjective **wellbeing** (e.g. Vestling et al., 2003), whereas this would not concern the majority of stroke patients who are post-retirement age. Maintaining QoL and promoting healthy, positive and successful ageing has become increasingly important, given the ageing population of most societies (Baltes and Baltes, 1990;

**qualitative methods**
concerned with describing (qualifying) the experience, beliefs and behaviour of a particular group of people

**wellbeing**
the subjective evaluation of a person’s overall life

Grundy and Bowling, 1999). The goal of healthy ageing approaches is to minimise dependency (physical and/or emotional), which, in turn, it is hoped, will reduce the ‘costs’ to society of healthcare provision for an increasingly ageing population. Studies of older people have found the life domains of importance to be good physical functioning, having relationships with others, and maintaining health and social activity. Compared with younger samples, older people are more likely to mention independence, or the fear of losing it and becoming dependent (Bowling, 1995b).

Assumptions of declines in subjective wellbeing with age have also been challenged by findings that life satisfaction does not change hugely over adulthood, and in fact increases between early 40s through to early 70s (in British but not German data reviewed by Baird et al., 2010), with a decrease then in later life as hypothesised. However Baird summarises findings from two national population surveys and not chronic illness populations and therefore cannot account for the effect of illness on such judgements.

Bowling and Iliffe’s (2006) study of the relationship between five ‘models’ of successful ageing and QoL among 999 adults aged over 65 years found that the broadest model of understanding of what it meant to have ‘aged successfully’ was most predictive of a person reporting they had a good quality of life, or not ‘a not good’ one. This broad ‘lay model’ encompassed biomedical (function), broader biomedical (e.g. roles and function), social functioning (social networks and support), and psychological resources (e.g. self-efficacy, optimism, coping) models, but added in socio-economic (income, capital) and environmental (safety, services, access) factors.

### WHAT DO YOU THINK?

Have you ever experienced a challenge to your quality of life? If so, how did you deal with it? Did one domain of QoL take on greater importance than it had previously and if so, why? Have the ‘weightings’ you attach to the different domains returned to their pre-challenge levels or has the event had a long-lasting impact on how you evaluate life and opportunities? Think about you ‘now’ compared perhaps with your parents. Do you think you see ‘quality of life’ differently to them? Consider what may change your judgements of quality of life in the future.

Therefore, while having a limiting illness influences the domains of importance in terms of judging one’s own QoL in that they become more focused on physical functioning and activity, social support and social contact, feeling that you have ‘successfully aged’ is about a lot more than that.

## Aspects of the illness and quality of life

There is a reasonably strong body of evidence showing that physical illness has an impact on a person’s reported QoL. For example, a review of the pooled data of 118 studies of health-related QoL in adults with type 2 diabetes (Norris et al., 2011) concluded that diabetes had a negative effect, particularly on physical function and general health domains of QoL, although of course pooled effects obscure the many individual different factors that influence individual experience of QoL. Aspects of the illness also matter: for example, pervasive and persistent pain and disability are generally found to be associated with a lower QoL, for example as reflected in depression levels, disability and use of healthcare (see Chapter 16 ☛). Ferrucci et al. (2000) investigated the extent to which disease severity in stroke, Parkinson’s disease (PD) or coronary heart disease (CHD) patients was associated with their health-related QoL and found, interestingly, that the relationship was non-linear in the stroke and CHD patients, and that only in the least severe stroke and most severe CHD cases was QoL in fact associated. In Parkinson’s disease, however, there was a linear relationship whereby severe PD associated with lower health-related QoL. In other words, severity of illness is not inevitably or consistently associated with lower health-related QoL, and disease-specific relationships need to be explored.

Illness type appears less important than the level of any resultant physical disability, most likely because physical disability challenges many of these other important domains – a person’s social, emotional, cognitive, economic, social and environmental functioning. For example, Blane et al. (2004) found that serious and limiting health problems were most strongly predictive of QoL in over three hundred individuals aged between 65 and 75, whereas non-limiting chronic disease did not affect QoL. They also found housing security, receipt of welfare or non-pension income and (for men only) years out of work to be predictive.

**Photo 14.2** Social participation can benefit healthy ageing.

*Source*: Shutterstock.

While being limited in terms of one's activities or roles is commonly predictive of poorer mental and physical QoL, quality of life is about more than this. For example, over half of the older people with long-standing limiting illness surveyed by Evandrou (2006) self-rated their health as good or fairly good. In fact Berg et al. (2006) highlights, that while subjective health ratings of the oldest-old (85 years +) correlate with other self-evaluations including general wellbeing or quality of life, anxiety and depression, they tend to be more weakly associated with objective health-related measures.

In those with neurological illnesses such as Parkinson's disease, cognitive dysfunction such as memory impairment or attentional deficits can disrupt key QoL domains. Furthermore, memory deficits can make it hard for some individuals to evaluate their current status against their former status in order to make meaningful QoL judgements (Murrell, 2001). Perhaps for this reason, patients with cognitive impairments have been the subject of less research attention.

Overall however, while a key global aim of interventions to enhance QoL, regardless of disease type, is the improvement and maintenance of physical and role functioning at all ages, QoL continues to be multidimensional.

## Culture and quality of life

Chapter 1 ☛ described how health itself is viewed slightly differently in Western and non-Western cultures, with individualistic Western views and more collectivist Eastern views of health being identified. In comparing data from studies of Chinese patients (typically collectivist) with Western (typically individualist) samples, Yan and Sellick (2004) noted cultural influences on many factors relevant to quality of life judgements, such as responses to pain, attitudes towards and use of traditional versus Western medicines and treatments, concepts of dependency, the use of social support and the culture of communication. As Bullinger (1997: 816) observed: 'If disease, as anthropological research suggests, is so very much culture-bound, how could quality of life be culture free?'. However, studies examining whether those in individualistic cultures can be differentiated from collectivist cultures in terms of QoL are a) limited in number and b) inconclusive. One might hypothesise that pursuit of subjective and hedonic wellbeing would be highlighted in the Qol of those from individualist cultures, with more eudaimonic wellbeing and social participation being highlighted in the QoL valued and reported by those from collectivist culture. A few examples are suggestive of this. For example, a study of Australian young adults (aged 18–25 years) found lower wellbeing among those with an individualistic orientation as compared to those with a collective orientation, and the authors suggest that Western social values around individualism may contribute to the growing prevalence of psychological health problems being witnessed (Humphrey et al., 2019). In a 15 country study including Europe, Asia, Australia, North and South America, Moons and colleagues (Moons et al., 2021) examined intercountry variation in 'sense of coherence' (a concept addressing perceived meaningfulness, comprehensibility and manageability of life, Antonovsky, 1987) and its relationship to QoL among a large sample with congenital heart disease. Their analyses found that individualism and collectivism strongly and significantly related to SoC, with collectivist cultures Japan and Taiwan reporting lower SoC. SoC was positively associated with QoL, with the strongest association being in Japan where over 30 per cent of the variance in QoL was explained. Such findings point to a need to recognise cultural belief systems and the potential effect they may have on health outcomes such as QoL and wellbeing.

## Aspects of treatment and quality of life

Treatment itself also influences QoL. Most studies examining the effects of treatment on QoL do so in order to either determine its impact on specific populations or compare which of several treatment alternatives is associated with the greatest QoL outcomes. In cancer, for example, scores on the POQOLS (pediatric oncology (child cancer) QoL scale; Goodwin et al., 1994) differed across groups receiving different treatments: for example, children undergoing intensive treatment showed poorer QoL than those in remission (Bijttebier et al., 2001).

Many treatment evaluations carried out as part of randomised controlled trials of new or comparable treatments include some indicator of QoL, such as symptomatology, physical functioning or return to work. Increasingly 'patient-centred' measures, PROMS (Patient-reported Outcome Measures) which invite patients to describe outcomes important to them in terms of their QoL, have been used (see Black, 2013, for a review). These measures can be disease-specific or generic (see later). The use of PROMS is now widespread, particularly in studies of cancer treatments, although being more accepting of their use does not automatically equate with their having influence on clinical decision-making (Meldahl et al., 2012).

In a UK study, for example, Watson et al. (2004a) examined the QoL outcomes of 481 leukaemia patients who had participated in a randomised trial of one of two types of bone marrow transplantation (BMT) (both preceded by intensive chemotherapy) compared with a course of intensive chemotherapy alone. At a one-year follow-up, those patients who received BMT reported greater fatigue, more problems in sexual and social relationships, and disruptions to work and leisure activities than those who received intensive chemotherapy alone. In addition, having BMT from a related sibling had a greater negative impact on the QoL indices than either unrelated donor transplantation or the chemotherapy group. A significant number of BMT patients may continue to experience significant functional limitations in the longer term, although the vast majority report their quality of life to be good to excellent (Broers et al. 2000). Supporting this, another Dutch study (Helder et al. 2004) found that the majority of QoL domain scores in young adults who had been children at the time of their BMT were in fact not significantly lower than that found in a comparison group of healthy young adults (although their general health was rated lower). This would suggest that the childhood experience of a serious illness requiring intensive treatment and a prolonged period of adjustment does not necessarily have long-lasting effects into adulthood, although larger-scale prospective studies which also consider other possible influences on the QoL of BMT survivors, such as social support resources, are required.

## Psychosocial influences on quality of life

The presence of anxiety symptoms or disorder has been associated with poor QoL among the physically healthy (e.g. Mendlowicz and Stein, 2001), and among those with physical illness, emotional responses unsurprisingly also have an impact- emotion is itself an identified domain of QoL. For example, depression and anxiety symptoms measured within 15 days of a heart attack both predicted low QoL at four months, with depression being the strongest predictor (Lane et al., 2000). Similarly, among 568 cancer patients, anxiety and depression were both related to the QoL dimensions of emotional, physical and social functioning, pain, fatigue (depression only), and global QoL, although as in Lane's study, depression was more strongly associated (Skarstein et al., 2000).

## ISSUES

### End-of-life QoL

While the majority of deaths take place in hospitals, the care of the dying more often takes place in patients' homes, until the point is reached where some home carers can no longer provide the necessary care or medication, and hospitalisation in nursing homes or hospices ensues. Among others, Elizabeth Kubler-Ross (1969) highlighted the psychological and emotional aspects of dying and the need to 'listen to the dying patient'. Kubler-Ross (1969) described a staged reactive process to dying, with initial shock and numbness following a terminal diagnosis being followed by a stage of denial and feelings of isolation, at which point individuals may become angry, blame others or even attempt to 'bargain' for goals they wish to meet before dying. Kubler-Ross describes the final stage as one of acceptance. However, acceptance is not always reached, highlighting as we have previously, that the proposed 'stages' do not hold for all cases.

Hospices were developed in the late 1960s from a recognition that traditional, medicalised, hospitals were not necessarily best placed to provide care to the dying. Hospices seek to provide care that facilitates an optimal QoL for both patients and their families as death approaches and this requires that patients are pain-free, experience little distress, maintain some dignity and control, and can maintain relationships with loved ones in a caring and compassionate environment. A good QoL at the end of life has also been found to encompass patients' need to remain as independent as possible so as not to 'burden' their carer (e.g. Gill et al., 2003). Carers' needs also should be supported in order that they are able to provide the patient with whatever support is needed during the final days and weeks of their life (see Chapter 15 ☛). Importantly, hospices need to acknowledge cultural variations in the 'rituals' that accompany dying and the expectancies family and friends may have. For example, positioning of the deceased to face Mecca is important to those of Muslim faith; the burning of sage by American Indians is an important ritual to prepare a dying person's soul for the afterlife. As Emanuel et al. (2007) note, the dying 'role' encompasses practical, relational and personal elements, all of which are necessary if the person is to move from a 'sick' role to the 'dying' role and adjust to it. Although taking on this role is emotional and accompanied by feelings of loss and grief, focusing only on the physical needs is insufficient. Do hospices achieve this?

Carers of patients who had died in hospices reported that 'their' patients were more aware that they were dying than did carers of those who had died in hospital, perhaps reflecting the ethos of openness encouraged in hospices. Openness regarding dying may enable greater preparation for death among patients and bereavement among family, which has, in turn, been associated with reduced levels of emotional distress (e.g. Chochinov et al., 2000). However evidence of hospices benefits to QoL were inconsistent in a review of palliative care provided to cancer patients either in a hospice, a hospital or at home (Finlay et al., 2002). With increasing emphasis on specialist nurses in hospitals, at least in the UK, hospital care is perhaps itself becoming more holistic, thus differences with hospices are less obvious. Certainly, within England and Wales the National Institute for Clinical Excellence (NICE) guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004) has long recommended that 'assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as at diagnosis; at commencement, during, and at the end of treatment; at relapse; and when death is approaching)' (Key recommendation 2).

Whenever a person is facing death, issues such as 'a good death' and 'dying with dignity' become salient and bring with them many ethical and moral debates. Research has consistently shown that older people do not fear death itself, as younger people do, but are more concerned about the process of dying and the fear of dying in pain or without dignity and self-control (e.g. Chochinov et al., 2002; Strang and Strang, 2002). A 'good death' in terms of the quality of the death experience is also important to the bereaved, to reduce any lingering anger or resentment and enable the grief process to be a more positive one (Tedeschi and Calhoun, 2008). Difficult questions arise, such as: When should treatment be stopped? How much can, or should a person endure, and for how long? Should a dying person who has been experiencing great pain or severe dyspnoea (breathlessness) be resuscitated if they become unconscious? Should a person facing a terminal illness and inevitable decline towards death be allowed to invite assisted suicide? How, and even where, an ill person chooses to die is inevitably a personal decision. Choosing 'when' to die is altogether more contentious, and even when an 'advance directive' from a patient is in place indicating their wishes for medical intervention (or not) when and if the time comes that they cannot communicate their wishes, health professionals may give priority to family members' preferences regarding end-of life care (Mowery, 2007).

The practice of non-treatment of a dying person – passive euthanasia – is generally acknowledged as an inevitable part of medicine; however, active euthanasia in terms of carrying out an action that effectively ends that life (such as administering a fatal dose of adrenaline) is much less common and varies by country (e.g. Van der Heide et al.'s review in six European countries, 2003) reflecting in part national differences in the legality of assisted suicide or euthanasia. In the Netherlands, GPs have been able to carry out these practices since 1991 (Onwuteaka-Phillipsen et al., 2003), while other countries have yet to make policy on this issue. For example, a study conducted in Wales (Pasterfield et al., 2006) asked GPs 'Do you think that the law on intentional killing should be changed to allow (a) physician assisted suicide and (b) voluntary euthanasia?' Of the 1,025 doctors who responded (a very reasonable 65 per cent of those invited to respond), 62.4 per cent did not favour a change in law regarding (a), and 55.8 per cent similarly did not favour a change of law regarding (b). In the face of such findings, it is likely to be some time before this contentious issue is resolved in terms of any legislation.

Human rights legislation, the desire for control over our lives and the fact that the world is facing an ageing population, many of whom will live many years with chronic ill health, suggests that issues regarding euthanasia are going to remain, and possibly grow, in most parts of the ageing world (Zucker, 2007).

Have your own personal experiences of death, if you have experienced any, influenced your thoughts on how you would choose to die, if that choice were available? What do you think would provide 'quality of life' at the end of life?

Leventhal and Coleman (1997) state that as well as being examined as an outcome, QoL needs to be considered as a process, itself influenced by various life domains, including the experience and perceptions of illness, symptoms and its treatment (see Chapter 9 ☛), and the importance attached to those perceptions at any given point in time. Changes in any of these determinants will influence changes in QoL. This process model has generally been accepted in psychological research studies where multi-ple determinants are assessed, as well as generic or specific QoL 'outcome' measures (see discussion of measures below). It is clear that various factors need to be taken into account when attempting to establish what 'predicts' QoL: the presence or absence of pain; the presence or absence of depressed mood; levels of social support, ethnicity and other background stressors that may be happening independently of the disease process under study.

## Coping and QoL

In terms of coping response, Carver et al. (1992) point out that avoidant coping is likely to be beneficial to QoL in situations where a person is unable to exert control, and they suggest that approach coping in these situations could lead to frustration when control is not forthcoming. Others suggest that maintaining a good QoL in relatively unalterable situations, such as that faced by individuals with chronic pain, may require individuals to cope by means of acceptance coping or positive reinterpretation. Supporting this, McCracken and Eccleston (2003), in a study of 230 adults with chronic pain, found that, while coping was weakly related to pain acceptance and unreliably associated with adjustment, those who *did* show acceptance of their pain reported higher QoL, including reduced pain symptomatology and disability, less depression and pain-related anxiety, a higher amount of time per day spent up and about, and a greater likelihood to be working. Such findings underscore the importance of the 'goodness of fit' of the coping strategy adopted to the current context, as also discussed in Chapter 12 ☛.

## Social support and QoL

In terms of resources upon which individuals may draw when faced with stress or the demands of illness, previous chapters have highlighted the crucial role of social support (Chapter 12 ☛) in coping and adjustment to chronic disease. However, the direction of causality between variables is not always clear. For example, in a study of 210 outpatients receiving treatment for epilepsy, regression analyses found that, independent of current physical health status, psychological distress, loneliness, coping and stigma perception contributed most significantly to the measures of QoL (Suurmeijer et al., 2001). However, disentangling the direction of relationships between mood, resources (or lack of resource if considering loneliness), coping variables and illness outcomes such as QoL requires studies with several waves of data collection, where change in the levels of support and adjustment, changes in coping responses, etc. can be assessed. In an attempt to do this, Burgoyne and Renwick (2004) assessed 41 Canadian adults with HIV three times over a four-year period and examined whether changes or stability in social support was associated with changes or stability in QoL. Although having a relatively small sample size, this study considers the dynamic associations between disease symptomatology, social support and QoL and explores the direction of causality between these factors. Do changes in social support lead to changes in QoL, or do changes in QoL lead to changes in social support? Slightly contrary to expectations, analyses revealed that both social support and QoL remained relatively stable over the four-year period. It did, however, decrease significantly for 40 per cent of the sample. If this finding were obtained in a larger sample, it would warrant further exploration to try and ascertain 'who' these 40 per cent were: i.e. did they differ from those for whom social support remained stable in terms of any personal or illness characteristics? Poorer mental functioning QoL scores tended to predict subsequent lower perceived emotional and informational support, but the directional relationship between physical functioning QoL and social support was unclear. Importantly, no strong longitudinal association between social support and subsequent QoL emerged. Furthermore, results did not reveal that changes in either QoL or social support were linked in the longer term (i.e. from year one to year four), although there was evidence of a link between the first and second year. Certainly the two measures were associated *within* each time point, with positive or negative changes in social support corresponding to positive or negative changes in QoL domains; however, the disappointing longitudinal predictive results means that social support and its effects on QoL, at least in this disease group, remains open to debate.

## Goals and QoL

QoL research has sometimes been criticised for the absence of a theoretical model around which to develop and test the QoL concept. One attempt to bring theory to bear has employed Scheier and Carver's self-regulation theory (see Chapter 9 ☛), which describes a process of goal attainment in the face of a disturbance such as illness (1992). It is proposed that the disturbance of personal goal attainment caused by chronic illness and its consequences is likely to influence a person's perceived QoL. Within the self-regulatory framework, event appraisal, appraisals of goal disturbance, outcome expectancies, appraisals of resources and coping processes all combine to influence QoL. Echteld et al. (2003), for example, found that among 158 patients who had undergone **coronary angioplasty**, disease-specific quality of life and positive affect three months after surgery were predicted by pre-surgery QoL, low stress appraisals and avoidant coping. Goal disturbance predicted disease-specific QoL and negative affect. Boersma et al. (2005b) also found that, following a heart attack, disturbance in 'higher-order' goals such as fulfilling duties to others, or having fun, was associated with anxiety, depression and a lower health-related quality of life. It may be that goals indirectly influence QoL outcomes by altering the 'meaning' a person attaches to their illness (Taylor, 1983; theory of cognitive adaptation to illness, see below), i.e. the extent and way in

coronary angioplasty

a procedure where a small balloon is inserted into the blocked coronary artery of a person with atheroma which a person understands the implications an illness has for themselves, their relationships and their future and as such has been shown to influence wellbeing and adjustment (Walker et al., 2004). Examining personal goals (both day-to-day and higher-order goals) and their attainment or non-attainment as a result of ill health is important if we are to better understand why people rate their QoL in the way that they do when given standardised QoL assessment tools.

## Expectancies and adaptation

One possible explanation for why some people with chronic illness report higher than expected QoL, sometimes at levels similar to that of healthy comparator groups, can be found in studies of adaptation which suggest that, when a situation is clear-cut and understood to be a permanent feature of one's life (e.g. bereavement, loss of a limb, an incurable illness), adaptation is easier and better than when one believes their circumstances are temporary and may change (Herrman and Wortman, 1985). This paradoxical suggestion led to a fascinating study of life satisfaction conducted by Smith and colleagues (Smith et al., 2009). They compared patients who had all had surgery resulting in the bowel being bypassed so bodily waste was passed via a tube to an external receptacle (therefore the 'disability' is the same), but one group had a temporary and reversible colostomy (also known as an ileostomy, reversed if the condition improves), the others, a permanent colostomy. Following patients to one and six months post-surgery, and controlling for the underlying condition, the main hypothesis that QoL would increase more over time for those with permanent colostomy than for those with a temporary colostomy was strongly supported. Those with a reversible colostomy reported higher initial life satisfaction (although not significantly so), but it did significantly decline over time, whereas the permanent group's life satisfaction increased.

Such findings are not consistent with models of adaptation that assume that negative reactions fade with time merely because of continued exposure to a negative stimulus (Diener et al., 2006). Crucially, the authors suggest that such findings highlight a role for cognitions, particularly expectancies of an improvement in circumstances, which paradoxically may impede adaptation. They argue that the motivation to cope may vary in these two groups and that looking forward to the potential of surgery being reversed at some point in the future may deter the person from adapting positively to current circumstances, as they are constantly comparing their current state with one yet to be achieved. Unfortunately the study does not explicitly assess these expectations, for example by assessing hope, nor does it assess the other possible illness-specific beliefs that may also explain differences in life satisfaction and quality of life ratings. In spite of this, however, findings suggest that health professionals' communications about prognosis should avoid being unduly optimistic about change, as this may instill false hope that is detrimental to patient adjustment. Hopefully, more and larger studies will pursue this research question further before we turn away from the newly burgeoning field of positive psychology (see Chapters 11 and 12 ☛) and accept that no hope may be better than hope!

In 'Issues' we address the question of whether or not QoL is attainable at the end of life, as a result of either ageing or terminal illness.

### WHAT DO YOU THINK?

When Christopher Reeve, aka Superman, was asked 'How would you rate your quality of life?' having been confined to a wheelchair following a horrific spinal injury, he replied 'I would say better than good. I would say it's, you know, good plus. I wouldn't say excellent because there are limitations . . . '

Illness, or even being totally paralysed from the neck down in the case of Christopher Reeve, does not inevitably lead to a poor evaluation of one's QoL. QoL is based on many things other than subjective health factors, including, for example environmental indicators, such as traffic, pollution, the housing market, and social statistics regarding leisure activities, consumer-good ownership, crime, educational attainment and unemployment. Using such data to provide an 'objective' estimate of 'quality of life, the World Population Review (2021) found Denmark, Switzerland, Finland, Australia and the Netherlands constitute the 'top five' for QoL, where the UK is ranked 19th, just above Lithuania. In this chapter we argue that QoL is a subjective construct – should we pay much attention to such rankings? Are such 'league tables' there purely to feed the media with buckshot to fire at our politicians, or do they raise real concerns about the health and social care systems and environmental policies of our countries?

# Measuring quality of life

There are several reasons as to why QoL assessment is a useful clinical practice (e.g. Higginson and Carr, 2001), including:

- *Measure to inform:* increased understanding about the multidimensional impact of illness and factors that moderate impact will (a) inform interventions and best practice, and (b) inform patients about treatment outcomes or possible side effects in order that they are 'prepared' for them, or so that supportive resources can be put in place. Descriptive data from QoL studies can also be used to inform patients and their families about likely treatment experiences so that treatment choices can be made. For example, Cocquyt et al. (2003) reported inconclusive evidence that breast-sparing procedures have better QoL and psychosocial outcomes than mastectomy (although some studies find better body image and sexual functioning in those with breast-conserving therapy) – such information can be presented by healthcare providers to help patient decision-making.
- *Measure to evaluate alternatives:* QoL measures may be used as a form of clinical 'audit' to identify which interventions have the 'best' outcomes – for the patient, but also often in relation to costs. Medicine often employs the health economics concept of quality-adjusted life years, or QALYs (number of years or proportion of year achieved with a good QoL following a given intervention). Different treatments may increase length of life and its quality to varying degrees, and when calculated these weightings can be assessed against the actual treatment cost (i.e. value for money). QALYs can inform medical treatment decisions: for example, two cancer treatments may offer the same survival benefits, but different QoL and QALYs during and after treatment.
- *Measure to promote communication*: while unlikely to be the primary motive for conducting QoL assessments in a clinical setting, doing such assessments may enable health professionals to address areas that they may not otherwise have done: for example, about treatment satisfaction, treatment or illness impact on family interactions, social or sexual functioning. Taking a more holistic view of the impact of illness or treatment upon patients can help healthcare to be responsive to individual patient circumstances or needs.

Whatever the motive for assessing QoL, a major issue faced by researchers or clinicians is which instrument or method of assessment to use. As noted by Carr and Higginson (2001: 1,359): 'if they [standardised measures] do not cover domains that are important to individual patients they may not be valid measures for those patients'. Also, clinicians need to feel confident in their interpretation and potential benefit to their practice, which evidence suggests they are not (e.g. Meldahl et al., 2013). If we accept that QoL is a multidimensional, dynamic and subjective construct, measurement is inevitably going to face many challenges!

## Generic versus specific QoL measures

The global domains of QoL described by the WHOQOL group have received empirical support; however, a question remains as to whether to adopt a generic, or global, measure of QoL which assesses concepts relevant to all illness groups or to adopt a measure specific to the illness being studied. As well as the WHOQOL-100 or WHOQol-Brev, commonly employed generic measures include the Medical Outcome study short form 36 (SF36, Stewart and Ware, 1992); the Nottingham Health Profile (NHP; Hunt et al., 1986); and the EUROQOL (Euroqol Group, 1990). In terms of disease-specific measures, an increasing number are available (see Bowling, 2005), including for people with cancer (e.g. EORTC QLQ-C30; Aaronson et al., 1993; Cocks et al., 2008, or the FACT-G, Cella et al., 1993; Holzner et al., 2004), asthma (e.g. Hyland et al., 1996), arthritis (e.g. AIMS-1, 2; Meenan and Mason, 1990) or Parkinson's disease (see review by Marinus et al., 2002).

There are disadvantages and advantages to both types of measure. Generic measures allow for comparison between different illness groups, but may fail to address some unique QoL issues for that illness. For example, the European Organisation for Research and Treatment of Cancer (EORTC) developed a cancer-specific tool (EORTC QLQ-C30) not only to assess quality of life

**Photo 14.3** Christopher Reeve aka Superman, rated his quality of life an 'better than good' in spite of being confined to a wheelchair.

*Source*: Featureflash Photo Agency/Shutterstock.

issues relevant to most people (see Table 14.1) but also included cancer-specific supplementary modules concerning fears of recurrence or of treatment side effects (Aaronson et al., 1993). In HIV infection and AIDS, issues such as HIV testing and the results process, and disclosure of a positive diagnosis to others, are addressed in a tool developed out of the previously mentioned WHOQOL (the WHOQOL-HIV) (O'Connell et al., on behalf of WHOQOL-HIV group, 2003).

Disease-specific measures therefore have 'added value', but they do not allow for the same amount of between-illness comparability which considers, 'Is the quality of life reduced more by cancer than by heart disease?' – a question of interest perhaps to those considering funding allocations or developing community support resources, for example.

## Individualised QoL measures

Another option is to take an individualised approach to assessing QoL which allows respondents to choose the dimensions and concerns relevant and of value to them (as is the goal of PROMS, see earlier) –not everyone will rate health, social life or work highly, for example! Demonstrating that QoL ratings can be obtained without using a questionnaire, Stenner et al. (2003) adopted a technique known as 'Q-sort' whereby 90 healthy participants (white, employed adults under 65 years old) sorted a collection of 52 statements about QoL into piles according to their importance to them (least important, neutral, most important). Within these three piles they then sort each item on a scale ranging from −5 least important, through 0 neutral, to +5 extremely important. Participants then examine their unique 'Q-sort' and discuss why they ranked items as they did, and whether they believe their ranking accurately reflects their personal view about QoL. Eight significant factors emerged that were interpreted as reflecting distinct constructs of the meaning and personal relevance of QoL *for this sample*: happy families; standing on my own two feet; emotional independence; just do it; life as a positive challenge; in God we trust; staying healthy enough to 'bring home the bacon', and 'You can't choose your family'. Demographic influences on these emergent factors included younger participants rating standing on their own two feet and being independent and in control more highly than older participants; whereas older participants, more often married, rated happy families and their relationships and support more highly. Many other differences existed, for example, in the extent to which mental wellbeing was valued in comparison to physical health. Furthermore, study findings highlight that different strands of QoL interact, and that causal sequencing seems likely: in other words, psychological aspects may influence the reported social, financial and physical aspects, and vice versa.

This 'idiographic' approach is also taken in specific assessment instruments: for example, the schedule for the evaluation of individual quality of life (SEIQoL; O'Boyle et al., 1993; Joyce et al., 2003). This is not specific to

**Table 14.1** Assessing quality of life – examples from the EORTC QLQ-C30 (version 3)

(NB: This is NOT the full scale: do not use in research)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no ‘right’ or ‘wrong’ answers. The information that you provide will remain strictly confidential.

| | Not at all | A little | Quite a bit | Very much |
|---|---|---|---|---|
| (2 examples of 5) | | | | |
| Do you have any trouble taking a *long* walk? | 1 | 2 | 3 | 4 |
| Do you need to stay in bed or a chair during the day? | 1 | 2 | 3 | 4 |
| DURING THE PAST WEEK: | | | | |
| (10 examples of 23) | | | | |
| Were you limited in doing either your work or other daily activities? | 1 | 2 | 3 | 4 |
| Were you limited in pursuing your hobbies or other leisure-time activities? | 1 | 2 | 3 | 4 |
| Have you had pain? | 1 | 2 | 3 | 4 |
| Have you had trouble sleeping? | 1 | 2 | 3 | 4 |
| Have you lacked appetite? | 1 | 2 | 3 | 4 |
| Did you feel tense? | 1 | 2 | 3 | 4 |
| Have you had difficulty remembering things? | 1 | 2 | 3 | 4 |
| Has your physical condition or medical treatment interfered with your family life? | 1 | 2 | 3 | 4 |
| Has your physical condition or medical treatment interfered with your *social* activities? | 1 | 2 | 3 | 4 |
| Has your physical condition or medical treatment caused you financial difficulties? | 1 | 2 | 3 | 4 |
| FOR THE FOLLOWING QUESTIONS PLEASE CIRCLE THE NUMBER BETWEEN 1 AND 7 THAT BEST APPLIES TO YOU | | | | |
| How would you rate your overall health during the past week? | | | | |
| 1 2 3 4 5 6 7 | | | | |
| very poor excellent | | | | |
| How would you rate your overall quality of life during the past week? | | | | |
| 1 2 3 4 5 6 7 | | | | |
| very poor excellent | | | | |

*Source*: From EORTC Quality of Life group http://groups.eortc.be/qol/questionnaires_qlqc30.htm For permission to use contact: Quality of Life Department, EORTC European Organisation for Research and Treatment of Cancer, AISBL IVZW, Avenue E. Mounier, 83/11, 1200 Brussels, BelgiumWebsite: http://groups.eortc.be/qol.

health and invites individuals to identify five aspects of life that are important to them (i.e. ‘What are the five most important areas of your life at present – the things that make your life a relatively happy or sad one at the moment. . . the things that you feel determine your quality of life?’). Individuals rate their current level of functioning on each, attach a weighting of importance to each aspect and rate how satisfied they are currently with that aspect of life. The aspects of life mentioned most often by the hip replacement patients in the original study were family, leisure activities, independence, happiness, finances and religion. Perhaps surprisingly ‘health’ was more often nominated by healthy control subjects, suggesting perhaps the importance of retaining health to those currently having it, and – among the patient sample perhaps a readjustment of life goals and values had led to the importance of health being downplayed – this, however, was not explored in the study.

Another individualised measure, specific to those with a health condition, is the PGI – the Patient Generated Index (Martin et al., 2007). This also asks individuals to name the (five) most important areas of their life, but unlike in the SEIQoL, the five *are* to be those that are affected by their health condition. These are then rated on a 0–100 scale (worst imaginable, to no effect, exactly as they would like it to be). This measure also allows for other aspects additonal to the five listed to be noted. Finally, in a novel addition, participants are given 60 points to 'spend' on buying improvement in any of their listed domains, and this spend is multiplied with the rating to provide a final score for the weight attached to that QoL domain. This really highlights the subjective value of different domains to different people. While the PGI is popular, it was not found to be concurrently associated in the hypothesised manner with illness perceptions in head and neck cancer patients (see Chapter 9 ☛) (Llewelyn et al., 2007), and PGI scores showed only moderate reproducabilty, responsiveness to change and correlation with other QoL measures among older heart failure patients (Witham et al., 2007). Perhaps further validation work with this measure is required.

While individualised methods of assessment acknowledge the subjectivity of QoL, such methods are time-consuming and relatively complex processes. Addressing the point that this could have excluded their use in certain populations, Jenkinson et al. (2001) adopted technology to make QoL assessment quicker, portable and possibly more adaptable to clinical situations. Their dynamic health assessment (DYNHA) system (see www.qualitymetric.com), which offers a short computer-based assessment where items are selected from a pool, dependent upon participants' prior responses to global questions. Many validated measures for both patient reported and clinical outcome assessment are now presented on this website along with information about their usage.

## Measuring illness experience and outcomes

Where circumstances allow, most studies use multiple measures and, as well as assessing generic and/or illness-specific multidimensional QoL, will generally also include unidimensional outcome measures such as 'patient-reported' assessments of mood, pain or disability ie PROMS. There is a natural limit to how many questionnaires can be 'inflicted' on an ill individual, and it is important that researchers are sensitive to this. Furthermore, a good research tool may not be an appropriate tool to administer in a clinical setting. For example, the functional limitations profile (Patrick and Peach, 1989), while a well-validated and commonly employed outcome measure, includes 136 items assessing 12 domains of potential illness impact (e.g. self-care, mobility, social functioning, communication and emotion), takes 20–30 minutes to complete, and is simply impossible in many clinical settings! In fact, the detection of mood disorders in hospitalised patients, such as clinical levels of depression, was often difficult for front-line nurses (see meta-analysis by Mitchell and Kakkadasam, 2011), which in part was due to the complexity of assessment instruments. The use of the simple Distress Thermometer has addressed this somewhat, although this is a screening tool only and not a full assessment (Mitchell and Kakkadasam, 2011).

In addition, illnesses that elicit a communication deficit, such as the receptive and expressive aphasias that are common following a stroke, make it difficult to carry out assessments of subjective perceptions, which often results in aphasic patients being excluded from self-report studies (e.g. Morrison et al., 2005). In these situations the other option is the use of proxy measures, although there are also limitations to those, as described below.

There is a proliferation of measures available to assess illness outcomes. These have been developed predominantly in the English language, meaning that for use in non-English-speaking countries, measures have to be translated. Bowden and Fox-Rushby (2003) reviewed the process of translating measures, in 23 countries across Africa, Asia, Eastern Europe, the Middle East and South America and concluded that in this process the meaning of items may be lost. In addition, using measures that have been generated predominantly from samples of Western populations assumes that words and concepts hold equivalent meaning across cultures, and that domains have equal salience. The fact that the incidence of disease and morbidity and mortality outcomes vary considerably between countries (see Chapter 1 ☛) creates differences in disease experiences which likely affect illness perceptions and QoL expectations..

The WHOQOL group addressed the issue of cultural equivalence in developing its measure, and similarly the cancer-specific QoL measure, the FACT-G (Cella et al., 1993) has received cross-cultural validation: for example, in a Korean sample (e.g. Lee et al., 2004). Lee et al. found that the physical, emotional and functional well-being dimensions had good construct validity, but that the social/family wellbeing subscale was problematic with items not loading together onto a coherent factor. This subscale assesses closeness to friends and partners, seeking of emotional support from family or friends, family communication, accepting illness on the part of the family, and sex life. The authors interpret these findings as evidence that the Korean women separated out family from friends in terms of what they offered to their wellbeing, with family communication and closeness fundamental, whereas the cancer was often kept from friends. This focus on familial support rather than that external to the family has been reported among Asian cultures also (e.g. Parveen and Morrison, 2009; Parveen et al., 2013). Such influences need to be borne in mind and the pooling of data obtained using multidimensional measures within mixed cultural samples avoided. Few studies have however addressed such specific differences in understanding of QoL.

The choice of which outcome to address in a research study and which measure(s) to use will necessarily be determined by a study's aims and by the practicalities offered by the research situation and the population in question. This ultimately introduces a lot of heterogeneity into the empirical literature which can make it quite difficult to compare across studies, or to translate research findings into clinical practice. While the dominance of some measures i.e. those considered gold-standard measures (e.g. for mood, for function, for QoL) may go some way towards achieving consistency in measurement, such standardisation bring with it the risk of losing information as to the very personal and individualised experience of illness, hence perhaps why qualitative methods are increasingly incorporated into large quantitative studies.

## ISSUES

### Allowing for response shift and social comparison

Consideration needs to be given to when and how often illness outcomes are assessed, and by whom. As described in this chapter, medical professionals are increasingly recognising the scientific evidence regarding the importance of psychosocial outcomes; however, there is a limit to how many outcomes and how often we can feasibly assess patients within the clinical context. In addition, findings can sometimes appear inconsistent with QoL, function or mood scores improving in patient reports over time even where no objective change in the condition has occurred. In fact, some authors have found individuals with limiting illness to rate their QoL higher than do healthy people (e.g. in diabetes; Hart et al., 2003). In trying to interpret this counterintuitive finding, we can either consider simply that it reflects the subjectivity of our measurements, or that illnesses do not inevitably limit a person's perceived quality of life. Alternatively, illness may itself create what is described as a **response shift**, i.e. illness causes people to recalibrate their internal standards, reprioritise expectations and perhaps change their life values (Schwartz et al., 2004) or reconstruct their identity to accommodate and take ownership of an illness identity (Jones et al., 2011; Tsarenko and Polonsky, 2011).

Yardley and Dibb (2007) nicely illustrated this in their longitudinal study of 301 individuals with Meniere's disease, a chronic although not life-threatening condition characterised by severe disabling vertigo, tinnitus and progressive hearing loss. When the scores obtained on the SF36 quality of life measure obtained at the first study time point were compared with the score given ten months later when participants were asked to look back to that first time point and score their quality of life 'then', there was a significant reduction in the reported level of general health, mental health, role-physical, and role-emotional attributed to the first time point. In other words, when looking back, these participants attributed poorer QoL across all SF36 subscales, except the 'physical health' one, to 'then' than they had reported

response shift

changes in subjective reports that may result from a reprioritisation of life expectations or recalibration of internal standards so that the construct being assessed is reconceptualised at the time. The *'then test'* was significant whereas the difference between the first time point and the second time point was not, i.e. the ten-month follow-up scores themselves did not differ from the baseline scores. This is response shift and is worth bearing in mind when conducting longitudinal studies. Yardley offers some explanation for this response shift by also showing that scores on a measure of goal orientation relevant to five broad domains of QoL *did* change over time with an improvement in participants' approach. Others have suggested that, when facing a serious or life—threatening condition, patients may 'scale-back' goals (Carver and Scheier, 2000; Sharpe and Curran, 2006). Qualitative studies support this by highlighting changes in life expectations, meanings, goals and priorities following diagnosis or during illness as described in this chapter. To better understand 'change' over the course of illness, the 'then-test' needs to be incorporated into many more future studies, including where the stressors are not necessarily life-threatening so as to ascertain whether response shift exists only in serious circumstances. We should not be surprised to find that such 'shifts' in perspective affects how questionnaire items are interpreted and scored at different time points, and, although there is likely to be an adaptive function, more evidence is needed in this regard.

Related to this, an interesting study by Sargent-Cox and colleagues (2010) assessed self-rated health in the large Australian Longitudinal Study on Ageing and identified that these judgements are often made in comparisons to others and that ratings can vary depending on who the comparator is. They found that self-comparative ratings ('Is your health now, better, about the same, or not as good as it was 12 months ago?') declined over a ten-year follow-up period, whereas age-comparative ratings (i.e. 'Would you say your health is better, about the same, or worse than most people your age?') stayed roughly stable for women but became more negative for men. This goes against the expected downward social comparisons (Festinger, 1954), whereby contrasting oneself to those worse off at the same age could be helpful in enabling one to dissociate from the 'ageing' stereotype and increase one's self-esteem (Wills, 1981) or contribute to adaptive coping (Buunk et al., 2006). *Identifying* downwards (as opposed to *contrasting* downwards), seen particularly among oldest-old men (85+ years) who compared themselves negatively against age-similar peers, is likely to create feelings of threat or anxiety. In contrast, young-old men (65 years) showed the expected increasingly positive age-comparative ratings. A global rating ('How would you rate your overall health at the present time?') which is commonly found to be predictive of many health outcomes, including mortality, significantly declined over time. Such findings have implications for the conclusions drawn. Unlike in this study where participants are *explicitly* invited to make comparative ratings, how are we to know whether social comparisons are *implicitly* enacted in the responses people make to our questions?

## Assessing illness experience and outcomes in children

McEwan et al. (2004) point out that adapting an adult questionnaire into a child version needs to consider cognitive limitations that make it difficult for young children to understand abstract questions such as those concerning life satisfaction or global wellbeing. Developmentally, and consistent with Piagetian thinking (see Chapter 1 (☛), the understanding of the more concrete domains of QoL (such as pain) may emerge as early as between four and six years of age, whereas the more abstract domains (such as feelings) emerge from around age seven. In addition, as Matza's very useful review of conceptual, methodological and regulatory issues highlights (Matza et al., 2004) it is 'important to ensure that items correspond to experiences, activities, and contexts that are directly relevant to the age of the sample' (p. 80). There is little to be gained from asking children about the impact of illness on general functioning where a distinction between school, play, at home, and with peers is likely to be needed.

A lack of child-validated QoL assessments, alongside a common assumption of cognitive limitation in children, has led to many studies using parents to complete questionnaires on behalf of their children – this is known as proxy measurement. However, parental 'proxy' reports in effect go against the principle of QoL being a personal subjective belief, as a parent may not share the same views as their child (Matza et al., 2004). Parent–child agreement has been shown to be greater for observable aspects of QoL, such as physical functioning, than for emotional or perceived social functioning. For example, a study of 100 children with congenital heart disease and their parents found that, while both parents and children reported reduced child motor functioning and autonomy when compared with healthy children, the children reported lower levels of emotional QoL than did their parents. In addition, parents reported that their child faced more problems than the children themselves reported (Krol et al., 2003).

By assessing 'visible' emotional distress, perhaps the reliability of parent proxy is increased as demonstrated for example in a study of QoL among young cancer patients (Bijttebier et al., 2001). Using parental proxy reports this study assessed predominantly observable aspects of QoL, including those related to emotions:

- physical restriction: e.g. my child has been able to perform as usual;
- *emotional distress:* e.g. my child has anger outbursts;
- *discomfort from medical treatment:* e.g. my child complained of pain after a medical procedure.

However, not all emotion is reflected in overt behaviour. A review of six studies where two sets of ratings were obtained found significant discrepancies between a physician's perceptions of patient wellbeing and QoL during the course of long-term (primarily cancer) treatment and that reported by the patients or, in the case of children, a parent (Janse et al., 2004). Given the evidence of divergence in reports, it is unclear who researchers should direct their questions to: it may be that assessing both the 'patient' and a significant other will give a more complete picture of the illness experience.

## Models of adjustment

Adjustment means different things depending on the perspective taken. For example, from a medical viewpoint pathology, symptom reduction or physiological adjustment would be considered; from a psychological viewpoint emotional wellbeing or a lack of negative emotions, cognitive adaptation (see below); and from a biopsychosocial perspective (as adopted by health psychology, see Chapter 1 ☛) adjustment is likely to consider pathology + emotions + cognitions + coping responses + the nature and extent of social adjustment or functioning. Walker et al. (2004) reviewed these three approaches or paradigms in relation to adjustment to rheumatoid arthritis, which has a clear pathology, is a typically painful and disabling chronic inflammatory disease of the joints, and has significant repercussions for both the sufferer and their families, and found that all three models have relevance. However, they conclude that the biopsychosocial approach best 'fits' the chronic disease experience (not just of rheumatoid arthritis) because of evidence of the critical role played by personal characteristics (e.g. optimism), appraisals (e.g. control), mood (e.g. anxiety) and coping responses in symptom experience and disease outcomes. Social factors such as the nature and availability of social support also play a significant role in the illness experience as described in Chapter 12 ☛ and in relation to caregiving (Chapter 15 ☛).

A well-cited example of a psychological model of adjustment was provided by Shelley Taylor (1983), who argued that the process of adjustment to threatening events, whether illness or not, centred around three themes:

- searching for meaning in the experience;
- attempting to gain a sense of control or mastery over the experience;
- making efforts to restore self-esteem.

This is known as a cognitive adaptational model in that, following a stressful event (challenge or threat), a person is motivated to face the challenges and be proactive in finding ways to deal with them in order to restore equilibrium in one's life. Unlike the stage models of response to illness described earlier, Taylor does not impose any sequencing on these three themes of adjustment, although it is likely that finding meaning in the experience will facilitate attempts to gain some control or enhance self-esteem.

Five related conceptualisations of adjustment to chronic disease were outlined by Stanton et al. (2001):

- mastery of disease-related adaptive tasks;
- preservation of functional status;
- perceived quality of life in several domains;
- absence of psychological disorder;
- low negative affect.

The latter two typically reflect emotions rather than cognitive adaptational tasks and adjustment is usually defined as the absence of these negative mood states.

Negative mood states, and emotional regulation (including expressed versus repressed emotion), as discussed previously can affect both physical and emotional adjustment to illness (and see also de Ridder et al., 2008).

Adjustment is dynamic and, to achieve it, finding meaning in one's situation and achieving some degree of control or mastery over it appear necessary. Finding meaning implies a degree of acceptance of the situation (see earlier section) which facilitates adjustments being made to expectations and goals that enable life to carry on (cf. Folkman and Moskowitch, 2004). Gaining a realistic sense of control need not mean actual control over the illness, but may simply mean control over some aspects of that illness: for example, over symptom medications or over dietary change. In fact, Taylor describes how the meaning, sense of control and restoring self-esteem may be 'illusions' which are nonetheless essential if adjustment is to take place. Much of adjustment is tied up with beliefs and coping as we hope to have made clear throughout this chapter, although the relationship is likely to be bidirectional.

It is, as we have described, possible to attain good adjustment and even personal growth in the face of challenging conditions. This may be in part due to the 'response shift' described in ISSUES, where individuals 'recalibrate' what is important to them and shift their priorities– perhaps this is at the crux of adjustment to changed circumstances, whether work or life stress (see Chapters 11 and 12 ☛) or illness as discussed here – we need to be flexible and respond to changing circumstances. Our theories acknowledge this, but our empirical evidence still needs to reflect this dynamism with many more studies assessing change in beliefs, expectances and responses over the course of an illness.

## SUMMARY

This chapter has provided evidence that illness can have a multitude of impacts on a person's life, whether physical, emotional or social, or a combination of these. In addition, positive outcomes are possible. In this chapter we have described a range of illness outcomes and a range of influences on them, from aspects of the disease and its treatment, to aspects of the individual such as their age, ethnicity, mood, coping responses or levels of social support. We have hopefully demonstrated that, in spite of some difficulties in measuring subjective health and illness experience, there is clear need for research and practice to look beyond clinical outcomes such as symptomatology and mortality, to more holistic psychosocial outcomes. This shift is seen in the growing inclusion of QoL assessment in clinical trials of treatments or in psychosocial interventions. For outcomes research, there is also the need to be sensitive to the needs of specific populations: for example children, or those from different cultures. And finally, as with attractiveness, wellbeing or quality of life are in 'the eye of the beholder', and this will continue to present challenges to interventions, as it is unlikely that 'one size will fit all'.

## Further reading

Stanton, A.L., Bower, J.E. and Low, C.A. (2007). Posttraumatic growth after cancer. In L.G. Calhoun and R.G. Tedeschi (eds) (2007). *Handbook of Post-traumatic Growth: Research and Practice*. London: Lawrence Erlbaum Associates, pp. 138–75.

This excellent handbook contains many chapters relevant to topics addressed in this textbook, but for this chapter I recommend you look at Stanton and colleagues' chapter for an account of how some good can come from what is often perceived as all bad.

Fallon, M., and Hanks, G. (eds.) (2006). The ABC of Palliative Care, 2nd edition, Oxford, Blackwell/BMJ Books.

This textbook covers all aspects of palliative care, from general principles to symptom specific care (e.g. around depression, breathlessness) in different populations (e.g. children, cancer patients) and bereavement. The importance of communication, carers and family, are highlighted. This text will be of interest to medical as well as psychology readers.

## Key papers

Park, C.L. (2010). Making sense of the meaning literature: an integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin*, 136: 257–301.

This paper usefully distinguishes between *searching* for meaning, a common response to stress and illness, and *finding* meaning, and the differential effects these two processes have for adjustment.

Compas, B.E., Jaser, S.S., Dunn, M.J. and Rodriguez, E.M. (2012). Coping with chronic illness in childhood and adolescence, *Annual Review of Clinical Psychology*, 8: 455–480.

This review highlights the importance of understanding processes of coping and adaptation to illness in children and adolescents. The paper focuses on control-based coping efforts.

Moss-Morris, R., Deary, V. and Castell, B. (2013). Chapter 25: Chronic fatigue syndrome, *Handbook of Clinical Neurology*, 110: 303–14.

This chapter presents an up-to-date summary of evidence relating to the experience of CFS in all its complexity and provides a good example of where cognitions and emotions interact with the experience of physical symptoms, and the implications this has for interventions.

## Weblinks

Type 'quality of life' into any search engine and you will get thousands of hits, some from health-professional pages, some from academia, while others will be papers from economists, policy makers and even governmental bodies. It is clear that QoL is a term in use in many domains outside psychology! Christopher Reeve (1952–2004), aka Superman, talking of his experience of spinal injury on the Muppet Show: http://www.youtube.com/watch?v=OzHvV.UGTOM

The Association for Death Education and Counseling website is produced by one of the oldest multidisciplinary organisations studying policy, practice and related evidence in the field of death and dying: www.adec.org

# Chapter 15

# The impact and outcomes of illness: families and informal caregivers

## Learning outcomes

By the end of this chapter, you should have an understanding of:

- the prevalence and nature of informal caregiving within family systems
- expectations of care and caregivers, and the issue of choice and willingness to care
- coping responses in the face of caregiving
- the consequences of informal caregiving, including caregiving benefits
- key personal, social and cognitive influences on caregiver experience and outcomes
- forms of caregiving which can be detrimental to the recipient
- the importance of dyadic and relational factors to psychosocial outcomes of patients and their caregivers

# In sickness and in health . . .

Would you willingly provide care for a loved one if they became chronically ill or disabled? There is a huge shift in the composition of society: ageing populations bring with them requirements for care, increased cultural diversity brings with it requirements for understanding different models of illness and informal care. Three in every five of us will likely experience someone in their family, whether parent or partner, becoming chronically ill and in need of support with aspects of day-to-day living where they did not before. While the majority of family caregivers are spouse partners, the prevalence of chronic diseases and disability increases with age and because women globally tend to live longer than men, it is likely that the need for care of older widows will fall to their adult children. Adult child caregivers also often still have employment, or late teenage dependents. An ill, widowed parent may not leave the adult child much choice in adopting a care role. Perhaps helping a parent or spouse dress or carry out household tasks would be acceptable, but what about helping them go to the toilet or bathe? What are the implications of such things for one's relationship? This chapter focuses on the nature of caregiving – the tasks involved, the motivations involved and the influences these have on the caregiver's experience and outcomes, and in turn on the quality of care provided to the recipient. Healthy, motivated, and supported caregivers are likely to offer a better quality of care.

## Chapter outline

In previous chapters, we have described both the theories and evidence around the wide range of individual and social factors that influence responses to a stressful experience such as illness (Chapters 9, 11 and 12 ☛). Our focus has predominantly been on the person experiencing the stressful event or illness directly, whereas in this chapter, we turn our attention to those who are the providers of social support to that person. In the preceding chapters, we have described support persons as buffering the stress of those with illness, however we now consider the impact of the illness on the physical and emotional wellbeing of the support persons, family or friend, many of whom act as informal caregivers. Who are these caregivers? What is the nature of caring tasks that they face and are they willing and able to take up the role when required or does society place unavoidable expectations on them?

We describe the personal and cultural influences on the uptake of caring and introduce the readers to concepts of filial obligation, reciprocity, and choice. We next present evidence of a significant amount of detrimental physical and emotional consequences of caregiving, but temper this with a growing and significant body of evidence describing positive outcomes of caregiving. We review the individual, cognitive, social and cultural factors that make it more or less likely for a care-giver to experience gain or strain and in doing so introduce the reader to critical, but often ignored factors such as relationship quality, values and motivations, and the nature of dyadic relationships, systemic transactions and shared perceptions and experiences. While relying on informal caregivers to bolster under resourced and over-stretched, health and social care systems, national policy and formal services recognise there is a need to acknowledge their valuable contribution. Health psychology and health services research is increasingly addressing the wider impact of illness on those other than the 'patient'. By dedicating a whole chapter to the caregiving experience, we seek to further contextualise illness within the core teaching of a health psychology programme.

## Illness: a family affair

People do not get ill in a vacuum: their illness exists within their immediate personal context and within their larger social network and culture. Not surprisingly, many of the wide-ranging effects of illness on the 'sufferer' described in the previous chapter (Chapter 14 ☛) can also be experienced by those closest to the ill person. The growing trend towards home care and day treatments places further pressures on families.

### What is informal care?

Alongside care provided by a professional or trained individual working in health and social care, typically paid for a certain amount of time and a specified role and on some form of employment contract (typically described as formal care), it is an assumption of many European health and social care policies that informal care will supplement formal care provision with regards to the management of those with long-term conditions (Triantafillou et al., 2010: 43). In fact, the Executive Summary of the European Commission's Informal Care in Europe report (European Commission, 2018) opens with the statement that 'Informal care forms a cornerstone of all long-term care (LTC) systems in Europe and is often seen as a cost-effective way of preventing institutionalisation and enabling users to remain at home' (p. 5).

While family members are generally involved in providing support to a family member if they become ill, some also therefore become that person's primary (main) caregiver: i.e. they are required to provide assistance above and beyond that which is 'normal' for their role (preparing a meal for a partner may be usual, whereas helping them to bathe may not be). Unlike formal carers, informal carers tend to be untrained family members or friends of the person with the illness or disability, who have no contractual 'hours' per se, no clearly defined limits to their role and variable financial recompense (European Commission, 2008).

Approximately 70 per cent of care recipients are aged over 65 years and thus the 'problems' caregivers are providing care for are predominantly (50–60 per cent) those of chronic disease or disability, but with significant proportions also caring for problems relating to ageing, such as dementia, and other conditions involving sensory impairment or mental health problems. Typical tasks of caregiving, as identified in the Carers UK State of Caring Survey (2014) involving more than 7000 carers, include providing:

- practical help, e.g. with cooking, doing laundry, shopping;
- emotional support, encouragement, and general watching over (by phone or in person);
- help arranging or coordinating medical/ care appointments, including the giving of medication;
- help with paperwork or financial matters;
- help with personal care tasks, e.g. dressing, bathing, eating and toileting;
- help with mobility, help to get in and out of bed, move around the house.

Caring tasks obviously vary according to the nature of the condition, its symptoms and any associated level of dependency, and as described later can have different impacts on the caregivers (for example, caregivers report finding the cognitive and behavioural changes associated with many dementias more 'burdensome' than providing practical support). The nature and extent of caregiving tasks will also depend on whether the caregiver lives with the care recipient or not, with co-located carers more likely to be involved in personal or physical care or the administration of medicines (see 'Issues' – Distance Caregiving).

National policy to assess caregiver needs annually in order to direct appropriate interventions to them exists, for example in England since the Care Act 2014. However, policy implementation falls short, with Carers UK 2019 State of Caring report finding that only 27 per cent of carers had been assessed in the previous 12 months, and even then it may not be achieving its' goals, as suggested by one participant who stated: 'They did it with my Mum present and so I wasn't able to speak freely- when I read back what they'd written it bore no resemblance to what I'd said- it was a box ticking exercise' (p. 11). Where carer needs are addressed, for example through providing them with information and skills to support their caregiving, this can be effective. For example, Kalra et al. (2004) found that training caregivers in providing physical care to their care recipient (stroke survivor), had positive effects in terms of reduced caregiver burden, reduced anxiety and depression. Notably, the training improved QoL for both the caregivers and their patients, highlighting that caregiver interventions are beneficial for both parties.

## Prevalence of informal care

Given the prevalence of chronic disease and disability, the need for informal care is growing as health and social care systems struggle to keep up with demand. While globally, it is estimated that over a fifth of the population will be aged over 60 by 2050, it is even higher in some regions of the world. For example, in China it is predicted that a third of the population will be aged over 60 by 2050, with the population of the oldest-old (80 years plus) multiplying five-fold to almost eight per cent of the population, both facts with implications for informal care provision in a vast country where families assume the primary responsibility (Feng et al., 2013). Furthermore, roughly 65 per cent of those at retirement age have at least two chronic health conditions (European Chronic

Disease Alliance, ECDA 2019). In the long term, many of these conditions will be managed in the home environment: for example, in Italy it estimated that two-thirds of the help needed by older people with care needs is provided by families (Triantafillou et al., 2010).

The available estimates as to the prevalence of informal care in Europe varies by country and ranges from around 10 per cent of the population (Romania) to 30 per cent (Greece) according to the European Quality of Life (EQLS 2016) Survey conducted across 33 countries (all EU countries plus 5 candidate countries) and almost 37,000 adults (see Table 15.1). However they define informal caregiving as caring for another person 'once a week or more' – quite a low threshold given that other studies typically specify caregiving in excess of 11 or even 20 hours per week, which can lead to differences in reported figures. For example in the EQLS data the UK has a figure of 19 per cent, whereas 16 per cent of adults interviewed as part of the Health Survey for England 2017 (Digital NHS, 2018) reported currently providing unpaid support to at least one person with long term mental or physical health problem, disability, or problems related to old age. Translating this into numbers, in the UK in 2018 it was estimated that there were approximately 7.6 million informal caregivers aged over 16 years (Social Market Foundation, 2018), a figure which has grown by a staggering 43 per cent between the 2011 census and 2019 (Carers UK, 2019), and which is expected to increase further. The turnover in caregiving is high, with an annual increase of over 2.1 million adults informal caregivers in the UK being matched by those who give up the role, for reasons of the care recipients' recovery, relocation into residential care, or death. Owing to population changes it is now estimated that three in every five people will be providing care for a family member or friend at some point in their lives. Simply stated, there is a growing care gap, between those needing care and available informal caregivers, for example adult children (Picard, 2015).

It is estimated that informal caregivers save the UK NHS and social services approximately £119 billion per year and a further £1 billion by virtue of the community-based self-help groups they offer! However, offset against this is the loss of caregivers to employment markets, tax revenue and the payment to them of welfare benefits (estimated at £5.3 billion a year by Age UK (2012). There are of course variations in the extent to which informal care is relied upon dependent on the prevailing national welfare systems, and an individual's ability to access private care – both factors which will affect the degree to which there is choice involved for the potential caregiver-we return to this issue later.

## Demographic characteristics of informal caregivers

The EQLS survey described above collected data from 33 countries and almost 37,000 adults and summarised the gender and age category distribution by country (see Table 15.1), where although there are differences, the overall trends are remarkably similar. It can be seen that

**Table 15.1** Informal carers as a % of total population, age and gender distributions

| Country | Total % | Male % | Female % | 18-34 years % | 35-64 years % | 65+ years % |
|---|---|---|---|---|---|---|
| Czech Republic | 9 | 9 | 9 | 6 | 11 | 9 |
| France | 16 | 13 | 18 | 11 | 18 | 14 |
| Germany | 23 | 20 | 26 | 12 | 28 | 24 |
| Netherlands | 18 | 13 | 23 | 10 | 23 | 17 |
| Spain | 16 | 13 | 19 | 14 | 19 | 11 |
| Sweden | 12 | 10 | 15 | 12 | 14 | 10 |
| United Kingdom | 19 | 16 | 22 | 18 | 20 | 19 |
| Belgium | 30 | 23 | 36 | 25 | 33 | 30 |
| Ireland | 10 | 9 | 11 | 6 | 13 | 8 |
| Greece | 34 | 29 | 39 | 33 | 35 | 34 |
| Italy | 17 | 16 | 19 | 12 | 20 | 18 |
| Poland | 20 | 18 | 21 | 7 | 26 | 20 |
| Portugal | 13 | 9 | 17 | 8 | 17 | 10 |
| Slovakia | 19 | 22 | 17 | 16 | 24 | 11 |
| EU28 overall | 17 | 15 | 20 | 13 | 20 | 17 |

*Source*: EQLS, 2016, selected countries and EU28.

typically a greater percentage of women in the population provide care than men (exception in Slovakia where more men provide care, and an equal percentage in the Czech Republic, possibly reflecting female labour market differences).

In a study of six European countries – Germany, Greece, Italy, Poland, Sweden and the UK (EUROFAMCARE, 2006) three-quarters of informal caregivers (76 per cent) were female, with, more recently Carers UK putting that figure at 81 per cent (based on responses to the annual State of Caring 2019 survey of 8069+ carers). Gender variation is also seen in the number of hours care is provided, with women even more highly represented in those providing care for 50 hours a week or more. In fact, in the UK, one in every five women aged 45–54 have caring responsibilities, compared to one in seven men of this age (Carers UK, 2019). Gender proportions also vary according to ethnic minority background, although it can be difficult to ascertain whether figures are representative for ethnic minority groupings due to poor culturally appropriate service provision or access, or use of other care services in these groups (e.g. Carers UK, 2014). Of the UK informal caregiver figures in the 2011 census (6.5 million), approximately 600,000 UK caregivers were from Black, Asian and minority ethnic groups (BAME) and as discussed later these populations may hold different beliefs around family and caregiving.

Gender differences in the types of care provided have also been relatively consistently reported, specifically findings that female caregivers were more likely than male caregivers to provide their family member with personal care (help with bathing, toileting, dressing etc.) (Maynard et al., 2018). In fact female caregivers may attend to a broader range of care recipient needs than male caregivers who may attend more to practical and less hands-on care needs (e.g. Lilly, 2008). The potential implications of care task type on caregiver outcomes, such as their own physical and emotional wellbeing, are discussed below.

In terms of age, using broad groupings, typically carers are less prevalent in the 18-34 years age group (apart from in Spain, where they outnumber the 65+ years category) (EQLS survey 2016, Eurfound 2017, Table 15.1). Most national surveys find that informal caregivers are aged predominantly between 45 and 64 (peak age 50–59 years), for example, forming 62 per cent of the State of Caring UK (Carers UK, 2019) survey. In the UK it is also estimated that there are approximately 180,000 caregivers aged under 18, which brings with it particular challenges as described in a later section addressing child or young caregivers. The typical age demographic however means that many carers will still be in employment, or possibly also still have dependent children. This is described as being in the 'sandwich' generation, providing care for young adult children (often students!) while providing care to a parent. Women at this point, more often than male caregivers, also find they have to give up meaningful employment (Carers UK, 2014; Evandrou and Glaser, 2014), although some will continue to work and combine the two roles (Hilbrecht et al., 2017); others, an estimated 15 per cent of caregivers overall will reduce their working hours in order to provide more care (Triantafillou et al., 2010). In a recent online survey of 1704 administrative workers in an Italian public company, more than 20 per cent were either caring for an elder, or 'sandwiched' between an elder care and child care, with this percentage increasing with employee age to a peak of 27 per cent among workers aged 55–64 years (Converso et al., 2020). There is a lot of juggling going on!

In terms of the intensity of care, definitions vary within the various surveys. However, Carers UK distinguishes between those that provide care between 1–19 hours every week (13 per cent of the 2019 sample); 20-–49 hours every week (23 per cent); 50–89 hours every week (17 per cent), and 90+ hours every week (46 per cent of the 2019 sample). In the large European Social Survey conducted across 20 countries in 2014, a distinction was made between 'informal carers' who spend '*any time looking after or giving help to family members, friends, neighbours or others because of long-term physical ill health or disability, long term mental il health or disability, or problems related to old age*' and 'intensive carer' with the latter being defined as care hours in excess of 11 hours per week. Of their 28,406 respondents (random general population survey, aged over 25 years) over a third were identified as informal carers (much higher than reported in the EQLS data above, Table 15.1), but only 7.6 per cent as intensive carers (Verbakel et al., 2017) – see also Figure 15.1)

It is also worth noting that for the typical caregiver, i.e. adult, middle-aged, a significant minority will have their own health problems, potentially exacerbated by their caring role – for example the prevalence of long-standing condition, disability or illness was found to be 63 per cent among caregivers compared to non-caregivers (51 per cent) in the 2019 GP Patient Survey (e.g. NHS England, 2019).

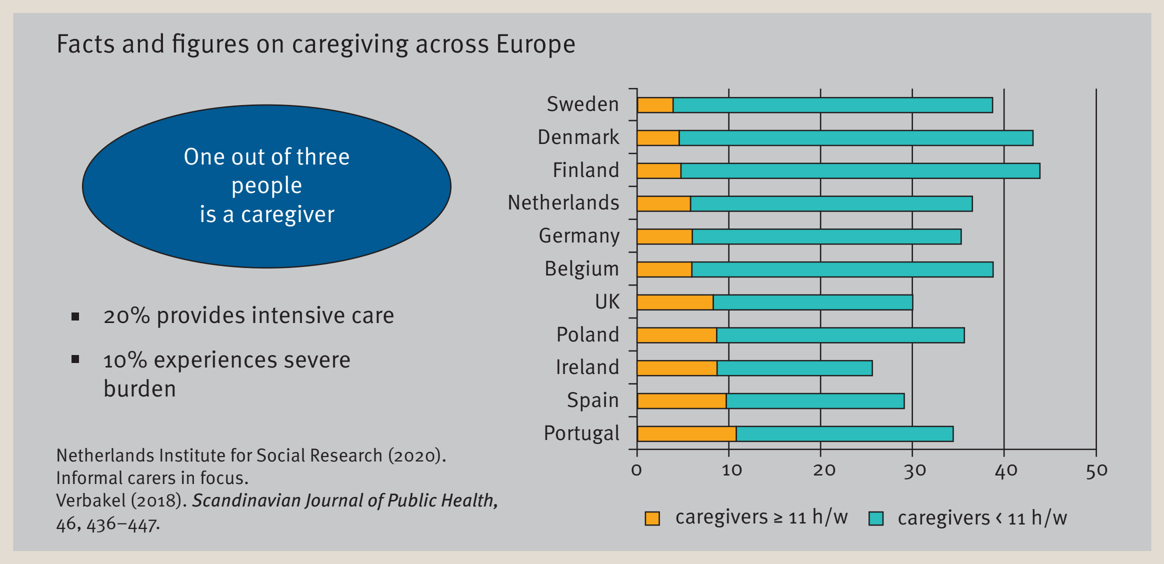


**Figure 15.1** Proportions of informal caregivers providing intensive care (>11 hours per week) across selected European countries

*Source*: 'M.Hagedoorn, UMCG, Keynote session, European Health Psychology Society Annual Conference, 2021 (Created based on data from Verbakel, 2018)'

## ISSUES

### Caregiving from a distance – less challenging? Not necessarily

With social trends moving away from family colocation, increased employment mobility and globalisation, traditional patterns of coresident family care is being challenged (Croucher et al., 2020). While over half (56 per cent) of the almost 6,000 informal caregivers surveyed shared the same household or building as the care recipient, this means that almost half did not (EUROFAMCARE, 2006). In the UK's State of Caring 2018 report (Carers UK, 2018) similarly around half of the almost 7000 caregiver respondents lived with the person they were providing care for, and of those that did not, over a third lived within walking distance, however 45 per cent lived within a 30 minute journey, a quarter lived more distant than this, with a minority of 6 per cent travelling more than two hours to provide care. The implications of not being co-resident with the care recipient in terms of the potential care type and intensity of support is obvious, however does the geographical separation itself influence the experience and outcomes of distance caregivers (DCG)?

In terms of tasks, DCGs are more typically shown to offer practical and instrumental support such as housework, home maintenance, shopping, coordinating care or transportation etc, rather than more hands-on personal care, although those closer by do offer this.

However, we currently know little regarding the experience of distance caregiving, in terms of what motivates it, maintains it, and the psychological and physical consequences of it (Bei et al., 2020). A few studies have suggested DCGs are motivated by similar reasons as collocated CGs, such as love and affection, family obligation, social expectation and reciprocity (e.g. Baldassar, 2007) however others suggest that guilt at being distant may motivate continued caregiving efforts from afar even if transnationally (e.g. Amin and Ingman, 2014). Distance caregiving has also been associated with feeling of inadequacy (e.g. Douglas et al., 2016) and higher levels of depression than seen among coresident caregivers (e.g. Li et al., 2019).

While efforts are being made to address the educational, support and psychosocial needs of caregivers in many nations, as reflected in policy guidelines, these tend to address needs assessment and support provision primarily for co-resident or local caregivers. It may be that to maintain the important role provided by DCGs that supportive interventions to address feelings of inadequacy, guilt or distress, need to be more innovative, possibly using technology to optimise connections between care givers and care recipients (Benefield and Beck, 2007) and potentially e-health interventions to support DCGs (see a review by Petrovic and Gaggioli, 2019).

**Photo 15.1** Having more time to spend with a partner as a result of illness can lead to a sharing of activities previously lost to the other demands of life. Spending 'quality time' together can strengthen some relationships

*Source*: Reg Charity/Corbis/Getty Images.

## What does being a caregiver mean?

Definitional issues exist in the literature as to who 'qualifies' as a caregiver, or as some prefer, 'carer'. For example, if you become ill does your co-resident partner or spouse, or your adult child who happens to live with you or nearby, and who seems willing to support you, automatically become labelled as your 'caregiver' or 'carer', or does their identity remain as your spouse or child, as support is an 'expected' part of that loving relationship, with its characteristics of mutual reciprocity of care? Does this reciprocity only extend to when you find yourself caring for a parent? Does a person only become a caregiver if they perform specific tasks that they would otherwise not have done, for example, help you to dress, or feed you, and do so with regularity? The latter is the approach taken more typically (e.g. Roth et al., 2015). However for children growing up with a sick or disabled parent helping out may be normalised, i.e. 'looking after Mum, or Dad, because that's what I've always done', and as such does this need a special label. Likewise a parent looking after a sick child, may reject the label, considering the care for their child as an expected part of their maternal/paternal role.

Thus, although we researchers 'label' those who are providing care to a loved one as 'carers' or 'caregivers', it does not automatically imply that the label of 'carer' or 'caregiver' is an accepted one. In fact even the use of these two words can be differentiated – the term 'carer' has been described as arising from the loving concern ('care') that constitutes part of a natural loving relationship – it has an 'affective' character – whereas 'caregiver' is thought to reflect more the 'doing' actions that naturally follow from caring (Pearlin et al., 1990).

Does labelling people who take part in our studies, or for use in policy documents, actually help? Certainly, criteria are needed if health and social care providers are to establish who is eligible for financial or practical support from the more formal care systems. For carer needs to be identified and financial or psychosocial support implemented, we need to be able to identify who they are, what care they are providing and how often (Arksey and Glendinning, 2008).

However, labelling the 'caregiver' as such risks changing the nature of the relationship between, for example, the healthy spouse and the one unlucky enough to have physical care needs, in that it fundamentally devalues the care recipient and fails to recognise the nature and quality of the relationship between the provider and the recipient and what the recipient themselves may be bringing to the reciprocal relationship (Molyneaux et al., 2011).

To my knowledge, we do not have a study of the perception of the label from the care recipients' perspective. However, examining the caregivers' perspective, Hughes et al. (2013) interviewed 40 'carers' of either a family member or a friend with multiple sclerosis about their experiences of MS from the point where the illness became apparent to them. Using identity theory to analyse the interview transcripts, these authors found four, sometimes overlapping, categories of self-identification with the label 'carer':

- those who *'embraced'* the carer identity as congruent with their other identities (regardless of whether support provided was emotional or practical);
- those who *enforced* the identity but in discord with their other identities (e.g. partner, sibling, child) with an acknowledged loss of self and of the spousal role;
- those who *absorbed* a partial carer identity but with ambivalence, pragmatism and flexibility depending on the needs of the day ('I'm just my dad's son looking after him. But if I'm speaking to somebody I'll say I'm his carer because that's what I'm doing. It's a role that I'm playing');
- those who *rejected* the carer identity in favour of holding on to their relationship identity: i.e. while acknowledging they may be described as a carer by others, they did not internalise this identity.

It was clear in this paper that identification with a label and a role is not straightforward: different identities took on different saliences, depending on both the relationship type, the gender of the caregiver, and the nature of the caregiving tasks – which in multiple sclerosis can fluctuate considerably. In fact those less 'typical' caregivers – adult child, sibling, appeared to embrace the role more than those more typical caregivers – spouses. This may relate to feelings of social obligation and assumptions regarding willingness to care which we return to later in the chapter.

We use the term(s) (carer/caregiver) in this chapter for ease of describing and contextualising our discussion with a literature that also uses one or other of the term(s), but the pros and cons of labelling in research is something we need to acknowledge.

# Expectancies of care

## Gendered expectancies

Gender bias in the caring role may be a result of the longer life expectancy of women (i.e. they remain healthy, and alive longer than men). It may also be due to societal expectations of caring being a 'natural' role for women, who are 'expected' to find family-oriented roles fulfilling, even in the absence of financial reward, whereas men may refrain from portraying an emotional, caring side are perceived as being more work-focused (Yee and Schulz, 2000; Feeney and Collins, 2003; Ussher and Sandoval, 2008). Gendered socialisation exists – the extent to which society places different expectations on males as compared to females is nothing new, and we have described how this can potentially influence their beliefs and behaviour at various points throughout this textbook – in relation to general beliefs about health, health behaviours, symptom identification and healthcare use, communication with healthcare providers. It is therefore no surprise that it may influence the nature and extent of caregiving. 'Provider' males and 'nurturer' females have led to an expectation of the care of a family member when ill falling to the female partner or relative. While certainly the gender imbalance has shifted, women do still dominate the caregiver statistics. A scoping review and gender-based analysis of caregiving in North America (Maynard et al., 2018) suggests that while caregiving may have become more socially acceptable for men, working males were less likely to also be providing intensive caregiving than working females and were more likely to be the secondary caregiver. One interesting question is whether providing care has any effect on gendered role identity (see later).

## Culture and caregiving expectancies

Most of the research examining cultural expectancies of care has been drawn from multicultural US populations, where Black Americans, Hispanic and Latino Americans are contrasted with White Americans (Pinquart and Sörensen, 2005), or within Asia, mainly between Chinese and Hong Kong (e.g. Feng et al., 2013) or in the UK between White-British and British South Asian (this population comprises mainly four communities – Punjabi Sikh, Pakistani, Bangladeshi and Gujarati Hindu) (Katbamna, 2004; Parveen and Morrison, 2009). These studies highlight cultural variations in aspects of societal values such as collectivism (versus individualism), and in belief and value systems including familism and filial responsibility or piety – filial piety (xiao, 孝) refers to the obligations of respecting, supporting and taking care of older family members (Tang, 2006) and is a core cultural expectation in Asian nations, such as China, Korea and Japan (Feng et al., 2013) although also strong in other ethnic groups, such as African American (Ejem et al., 2018).

In China, the long-standing and strictly enforced one-child policy (although in rural China sometimes a second child was 'allowed' if the first-born was female) that existed from the 1980s until 2015 meant that a typical three-generation family would consist of four elders (grandparents), two adult children (parents) and one (grand)child (a '4–2–1' family). Here the adult children assume physical and emotional caring responsibilities for four elders and one child. If the elders need long-term care because of chronic illness, the caregiving burden to adult children can be dramatic (Liu and Cai 1997, as cited in Feng et al., 2013). The lack of siblings in this culture has significant implications for caregiver outcomes, given the lack of shared responsibility when a family member, typically an elder parent, becomes ill. Unlike in South Asian cultures where care expectancies tend to fall on female family members (daughters first, then daughters-in-law), in China filial obligation first extends to the eldest son (although, if married, his spouse will be expected to support the care role).

## The issue of willingness to care

Care of family members needing it in the future will depend on spouses, adult children and other relatives, being available and willing to provide care. Furthermore, with smaller family sizes (people having fewer children), more women in the workforce, and reduced co-residence or geographical proximity of many families, society does face a challenge of meeting the needs of the elderly, ill or in need of care – referred to by some as the 'care-gap' (e.g. Pickard, 2015).

Being willing to care can be considered as a related but separate construct to being motivated to care, with willingness perhaps referring to more to a general attitude towards a behaviour, such as a particular caregiving task, and motivation referring to more goal-oriented attitudes responsible for initiating, guiding or maintaining behaviour (Ryan and Deci, 2001). Our motivations are perhaps what explains the 'why' of behaviour, whereas willingness may better explain the 'what' of our behaviour, however within caregiving studies the terms are often used synonymously, and it is a complex area – to try to explore the interlinkages we have recently reviewed these constructs from a theoretical and evidence based perspective, which interested readers may wish to pursue (Zarzycki and Morrison, 2020). For current purposes however we use whichever term or construct has been used in study referred to, and acknowledge that they may not reflect exactly the same attitudinal or belief measures.

Studies have typically distinguished between intrinsic motivations to care (e.g. principles, caring nature) as opposed to extrinsic motivations (e.g. out of guilt or expectation) (Feeney and Collins, 2003; Lyonette and Yardley, 2003; Quinn et al., 2010, 2012; Walker et al., 2019). Studies using this dualistic theory have pointed to the nature and quality of the relationship between the caregiver and recipient, motivations, and caregiver wellbeing being related (Lyonette and Yardley, 2003; Parveen, Morrison and Robinson, 2013; Sorensen et al., 2008; Williams et al., 2014). In Williams and colleagues' qualitative study several caregivers reported being willing to provide care because they perceived their pre-illness relationship with the care recipient to have been a good one, where others provided care as the preferred alternative to feeling guilty for handing care over to a formal institution, e.g. a nursing home. Lyonette and Yardley (2003), and Sorensen et al. (2008) also report an effect of relationship quality on motivations to care. In findings from studies that include ethnic minority caregivers (African-American, Hispanic and Asian-American caregivers; British Asian), a greater emphasis on familism and filial responsibility is often seen, born in part out of a sense of reciprocity for former parental care and support, but also out of emotional attachment (Pinquart and Sörensen, 2005; Parveen and Morrison, 2009) and thus motivations become more complex and multidimensional (for a review of theories of caregiving motivation and associated constructs, see Zarzycki and Morrison, 2020). However while differences in familism were found between British South Asian and White British caregivers in a study by Parveen (Parveen et al., 2013) this did not reflect in differences in willingness to care, with both groups reporting being equally willing to provide care for their loved one. Perhaps feelings of filial obligation should not lead us to presuppose willingness, a suggestion supported by the author's own qualitative work (Parveen et al., 2011).

In addition initiation motives are likely to be distinct from continuation motives, with studies pointing to possible shifts from altruistic motives of love and reciprocity, or a sense of obligation, to more egotistically oriented motivates (for example, keeping in touch so as to inherit; or more positively, staying as a caregiver in order to hold onto the sense of being needed and useful. While a review of qualitative studies of dementia care by Greenwood and Smith (2019) suggested that motives remain relatively similar, perhaps the nature of the condition and the stability or fluctuation in the care recipient needs may affect the stability or otherwise of caregiver motivations, as seen in a longitudinal qualitative study with carers of those with varying conditions (Morrison and Williams, 2020). In this study one carer, who initially was determined to provide all the care for her mother with progressive dementia herself, found that as her mother's condition progressed and needed more nursing care, her anxiety about managing to care grew. When she subsequently conceded to accepting formal help and gained some independence this actually increased her motivation to continue co-caring, rather than see her mother enter a nursing home. As with coping (see Chapters 9 and 12 ☛) caregiving is dynamic, and also to benefit wellbeing, needs to be flexible. Motives can be intrinsic, extrinsic or a combination of both, and also have been considered in terms of various aspects of 'reciprocity', for example 'giving back' to a parent, 'paying forward' or 'getting back' in the expectation of reciprocal care if you yourself become ill at a later point (e.g. in a spousal relationship, or in caring for a child).

**Photo 15.2** Caregiving for an elder

*Source*: Chuugo/Shutterstock.

The majority of caregiving studies have involved those who were already providing care and therefore motivations for caring are informed by the actual experience of care; however, in an interesting study with implications for the future (given how many of us may need to take on a caring role), Rohr and Lang (2014) addressed hypothetical willingness to care in relation to the gains or losses anticipated from the role among a sample of German adults (mean age 55 years, 77 per cent female), comparing 113 actual caregivers with 189 who expressed being willing to provide care in the future, 121 who were undecided, and 62 who rejected the notion. Those who expressed willingness to provide care, and those that were current caregivers, anticipated less losses and more gains than those who reported being unwilling to provide care. The willing group also anticipated similar gains to the actual caregivers, which was significantly higher than anticipated by those who were either unwilling or undecided about providing care. Those who were willing were also older and reported better subjective health. The anticipation of losses and low relationship satisfaction predicted potential unwillingness to care. Although these data are cross-sectional and don't address the complexities of carer type and relationship quality, the importance therefore of 'getting something back' i.e. perceiving potential gains from caregiving is clear. It may be that gain expectations will increase the likelihood of a person adopting the role in the future – longitudinal data is clearly required to explore further the predictors of transitions *into* caregiving. Gains from caregiving do exist, as we discuss below. It may also be the case that potential caregivers have preferences for providing some forms of care over others: for example, they may be willing to provide practical care but not assist with personal care tasks – this would require further research.

However, for many informal caregivers there may not be any clear options other than to provide the required care for their family member. Lack of choice, not having the freedom to choose to take up the responsibility of care (Al-Janabi, Carmichael and Oyebode, 2018), when directly asked of informal caregivers, has been shown to vary, for example from over 80 per cent of a sample of dementia caregivers in Ireland (Pertl, 2019), to 44 per cent among US caregivers of older adults (Schulz et al., 2012), and although only around 20 per cent of a sample of British caregivers studied by Al Janabi and colleagues (2018) felt they had no choice to provide care, only a third actually considered they had 'free choice'. When explored qualitatively, all five interviewees in Bolas's study of young caregivers (aged less than 18 years) (Bolas et al., 2007) stated that they had 'no choice' in taking up the caring role, admitted they would prefer not to have to do it, and while they felt the role was demanding, for some it was seen as inescapable.

## WHAT DO YOU THINK?

Disability and dependence is increasing, not only among those considered 'elderly' but also in those in late middle age who may live for a further 10, 20 or 30 years in a dependent condition. More often societies are turning to families to provide a solution to these growing needs. Gendered roles have generally changed hugely over the past century. Ask your sister, mother or your grandmother about their views on staying at home to care for a sick or dependent relative; ask your brother, father and your grandfather. Do the responses differ by generation? Do they differ by gender? Then consider your own situation. Are you already, or likely to be facing in the future, the need to provide informal and unpaid care for a relative? How does this make you feel? How do you imagine you will balance your various life roles if you take on an additional caring role? Are your projected life goals (likely to be) constrained by these anticipated caring needs? Do you worry about what will happen to your parents if they become chronically ill or develop dementia?

Has improved (but not yet perfect) gender equality in the workplace and an improved social status, led today's women to be less willing to care for a dependent family member than previous generations? Are men more open to the caregiving role now than in generations past? We are learning more about the consequences of willingness to care upon caregiver mental and physical wellbeing, but we know less about the implications of unwillingness for the recipients of their care, or of the implications for health and social care policy. These questions have significant psychological implications, but they also need social and political answers.

# Family systems and family members

The diagnosis of serious and/or chronic or disabling illness and subsequent tests and/or treatments can have a significant impact on family coping and on their levels of certainty for the future, and life goals (Sherman and Simonton, 2001). As described in the previous chapter, staged theories of patient adjustment to illness (e.g. Morse and Johnson, 1991) have been proposed. Bringing a similar way of thinking to those affected by stress (not necessarily illness) within the family, McCubbin and Patterson (1982, 1983) describe how pressures can disrupt or change the 'family system', with stages in a continuum of adaptation proposed:

1. *Stage of resistance:* where family members try to deny or avoid the reality of what has happened.
2. *Stage of restructuring:* where family members begin to acknowledge reality and start to reorganise their lives around the notion of a changed family.
3. *Stage of consolidation:* where newly adopted roles may have to become permanent, for example if recovery is not forthcoming; and where new ways of thinking (about life/health/behaviour) may emerge.

Relating this to illness more specifically, Rollands' Family-Systems Illness model (Rolland and Williams, 2005; Rolland, 2012) offers a systemic view of illness considering that, to be effective, a biopsychosocial approach to illness must acknowledge (a) the illness and its likely characteristics over time and (b) all persons involved in a family unit as they can 'in turn influence the course of an illness and the wellbeing of an affected person' (Rolland, 2012: 453) (see Figure 15.2). Observing the complexity of the mutual interactions between family members, Rolland suggests that positive and normative responses to illness in one of its members need to be explored instead of the more common focus on negative responses and outcomes. The goal of a family is to understand a given situation and any likely changes in it (due to the health condition or treatments, for example), in a way that enables them to continue to function as a family. This requires understanding of how the family and its component persons function together and separately, with any gendered or cultural norms and expectations of caregiving also acknowledged.

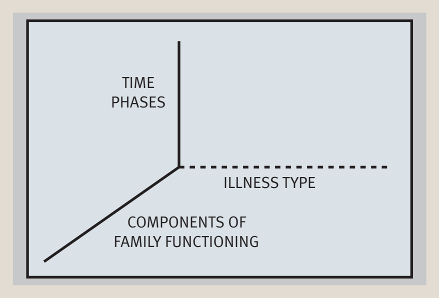


**Figure 15.2** Three-dimensional model representing the relationship between illness type, time phases and family functioning

*Source*: Rolland (1987a, cited in Rolland 2012).

Earlier work by Olson and Stewart (1991) highlighted three integrated dimensions of family system functioning: cohesion, adaptability and communication. Families who were balanced on these dimensions (i.e. those who work together and are affiliated and emotionally bonded with each other; adapt roles and rules in face of new situations, and communicate effectively) experienced better adaptation to life stressors, including illness. This is reflected in a study of the impact of a disabling stroke, where Palmer and Glass (2003) identify the need for families to adjust to new patterns of relationship, roles and communication styles and 'to accommodate the stroke survivor's functional and social losses while continuing to meet the psychosocial needs of the entire family' (p. 256). Their review highlights that the process of recovery from stroke, from a family system perspective, is about support and collaboration from and between family members, and that the absence of these can have detrimental effects on the wellbeing of both the stroke sufferer and their family members. In a qualitative study of stroke patients and caregivers, and also nurses, there was agreement that interventions while the patient was in hospital but continuing post-discharge were needed to boost caregiver resiliency and prevent chronic distress. Such interventions would help patients and carers develop problem solving, self-care, being in the moment/mindfulness, optimism/gratitude (see Chapter 14 ☛), building interpersonal communication and a support network (McCurley et al., 2019).

## Parents as caregivers

Studies of parental coping have highlighted the importance of within-family communications, as well as coping through the use of external social relationships, including relationships with medical staff and parents of similarly affected children. Different expectancies and coping responses are seen to have different implications for family functioning: for example, in relation to supporting an adolescent child with diabetes where it is important for a parent to get the correct balance between providing care and making informed decisions on behalf of a younger child and allowing the child to develop responsibility for illness management or aspects of it as appropriate to their age (Comeaux and Jaser, 2010; Compas et al., 2012; Law et al., 2013). Table 15.1 displays tasks faced by parental caregivers, described by parents of a child with cancer (Klassen et al., 2012), where it can be seen that potential tasks bring parents into contact with a range of authorities (healthcare and educational, for example), and require a significant amount of time commitment and effort to retain normality for other members of the family. While presenting these tasks as published, it is notable that several tasks listed as physical tasks have obvious emotional correlates: for example, dealing with child behavioural or emotional challenges, entertaining a sick child.

Where the illness or injury faced by a child has had a traumatic onset and faces difficult treatment, for example managing pain and tissue damage following an accidental burn, parental caregivers can experience significant post-traumatic symptoms- distress, guilt (particularly where a young child has been burnt in the home), fear for the child's future appearance due to scarring etc. Parental or caregiver anxiety and post-traumatic symptoms have been shown to influence child procedural coping and distress and even the wound healing that takes place – by delaying the natural process of skin repair (Brown et al., 2019). Caregivers it seems can transmit their anxieties onto care recipients, although it is as yet unclear whether this is via effects on child's own emotions, physiological responses or wound care adherence behaviours.

The influence of caregiver responses are also seen in adult dyads, as discussed later on in the chapter. Does this potential to impact on the care recipient suggest that caregivers should hide their feelings perhaps? Certainly we have evidence of gender differences in talking about a child's illness, with fathers seen to be more reluctant to do so (Eiser and Havermans, 1992) however early concerns were around consequences of this for paternal wellbeing. In a study comparing coping, anxiety and depression among parents of healthy children compared to children who were undergoing or who had completed cancer treatment, in both scenarios anxiety and depression were higher among mothers, however notably 59 per cent of non-responders to this study were fathers (Norberg et al., 2005) – suggesting perhaps either a tendency for fathers not to want to talk about their child's illness, or /also that the distressed fathers did not respond. There is some suggestion that some mothers 'gatekeep' the care of their child, resulting in some fathers feeling left on the periphery – this may help account for fathers' greater reporting of problem-focused coping and attempting to gain a sense of control over the situation, rather than talking about how they feel (Hill et al., 2009, cited in Turner-Cobb, 2014: 172).

Of course, it is not only when it is a child who is ill that families are affected. The incidence of most chronic and disabling conditions increases with age and therefore most recipients of informal care are adults. Across Europe, drawing from SHARE 2015 (Survey of Health, Ageing and Retirement in Europe) just over a fifth of informal caregivers were spouses, and 60 per cent were either children or children-in-law. Notably female spouses are more likely however to be solo carers whereas male spouses are more likely to share care with other family members (Bertog and Strauss, 2018).

## Spouses as caregivers

Typically in conditions with onset in middle age or among the young-old such as stroke or Parkinson's disease, the primary caregiver will be a partner or spouse, who themselves may have health problems and comorbidity (Adelman et al., 2015). Among the older- and oldest-old, however, many individuals, particularly females, will be widowed, thus care typically falls to an adult daughter. However, the gender gap in expected life expectancy narrowing perhaps more male spouses will survive to face taking on a caring role (Triantifillou et al., 2010).

Spousal caregivers tend to live with the person they are providing care for, and this in itself explains why studies of the impact of caregiving commonly points to more deleterious effects of caregiving for this group than others (e.g adult daughters). By nature of co-habiting, spouses will implicitly assume a caregiving role, provide more hours of support, spanning the range of needs over a day and night than non-resident family. With this in mind some have suggested that spousal caregiving is more normative and thus less likely to be as stressful as caring for an elder (Chappell, Dujela and Smith, 2014). In couples, support tends to come from each other in the first instance and the supportive relationship is generally reciprocal, although relationship quality does differ and this should not be assumed.

Furthermore co-residing with the care recipient leaves little room for time away from the role and thus others have shown that spousal caring is more challenging than that faced by non-spousal caregivers (e.g. Kim et al., 2012). There may even be gender differences here with Penning and Wu (2016) finding that for women, spousal or child caregiving is more stressful and detrimental to caregiver mental health than caring for parents or others, whereas for men, while caring for a spouse or child was considered more stressful, the effects on mental health did not differ significantly from care for parents or others.

## Child and adult-child caregivers

Children and young people (generally defined as under 18 years), and in fact middle-aged sons or daughters providing care for a parent, face particular issues when providing care atypical to that child–parent relationship – for example, it is not typical to help feed, dress or toilet your parent.

In terms of child caregivers more specifically, in the UK alone a population Census (2011) indicated that almost 178,000 persons aged under 18 years had caring responsibilities; many more live in a household with an ill or disabled family member but who do not appear in these figures. While the majority are providing under 20 hours of care, many are caring at a high intensity, yet little is known about the full long-term impact of caregiving on these child caregivers. Some interesting qualitative findings suggest that for school-aged caregivers, their minds are distracted by thoughts of the caregiving demands and the care recipient even when they are away from the home. For example, Bolas et al. (2007) interviewed three female (aged 14, 16, 18) and two male caregivers (aged 14 and 16) about their caregiving experiences. One young man caring for his Mum said, ‘Really you’re a carer from when you wake up in the morning to when you go to sleep at night. Even if you’re not in the house you’re having still basically thinking about what’ve got to do when I get home, well really what I’ve got to do so it never really leaves me mind.’ In such ways the academic performance of child caregivers and potentially their future potential is undermined. Socially, they also suffer. Interestingly, it has been observed that many young carers do not recognise themselves as carers at the time, responding simply to caregiving requests of their parent in a reciprocal manner for other forms of care received from the parent, and not perhaps knowing that such behaviour is not the norm (Smyth et al., 2011). Due to this, it may be hard to ascertain the true prevalence of young carers in a community.

The largest group of informal carers in the ageing population in Europe and globally comprises either adult children or children-in-law (EUROFAMCARE 2006). In a culture such as China, caring for an elder when needed is an expectation almost upheld by the constitution – the government lays the responsibility for care on the shoulders of the family, and filial obligation means that adult children are turned to to fulfil their caregiving responsibility (Feng et al., 2013). In China, this can often involve co-residing with the parent; however, in non-Eastern cultures it is more likely that the adult child will live elsewhere – which is why many studies report lower levels of caregiver burden in adult children compared to co-resident caregivers, usually spouses. Caring for a parent as an adult-child arises out of similar emotional investment as perhaps spouses have, but the potential for a reversal of roles – providing personal care for a parent where once it was received as a child, and the likelihood also of having to juggle other dependants – makes caring for a parent highly demanding. In fact adult-child caregiving is often thought to be inherently more stressful than spousal caregiving because these caregivers often have multiple roles and perhaps ‘view caregiving as extra work (role overload) and experience the burden of role reversal’ whereas spousal caregiving is more normative (Chappell, Dujela and Smith, 2014, p. 463). A qualitative study of Canadian adult-daughters in the context of providing care for a parent following a stroke support this sense of overload (Bastawrous et al., 2014). For these women, juggling multiple other roles on top of caregiving created strains in valued relationships with children and partner, and decreased participation in valued social activities (work and leisure).

As mentioned previously the gender of the adult child care-giver may have an effect on the nature of caregiving tasks carried out, with sons more likely to provide practical support such as running errands, providing transport, than personal care or housework support (Pinquart and Sorensen, 2006); however, this may also depend on the gender of the care recipient, with evidence that female caregivers may be less comfortable providing personal care to fathers. A large American study of almost 3,000 caregivers (Longitudinal Study of Aging) found that, over a two-year follow-up period, son caregivers were more likely to transition a parent with impairment in activities of daily living into residential care than a daughter caregiver (likewise did husbands more often than wives) (Allen et al., 2012).

## Supportive relationships

There is a clear need to evaluate the nature and effects of supportive relationships, because the presence or absence of perceived and received social support from a loved one can significantly influence a person's response to, and outcomes of, stressful experiences, such as illness. As described in Chapter 12 ☛, there is consistent evidence as to the benefits of being part of a functional supportive network as opposed to being socially isolated.

Benefits of social support are to both the care recipient and the caregiver and include, for example:

- increased care recipient adherence to treatment and self-care (e.g. Toljamo and Hentinen, 2001);
- better caregiver emotional adjustment, including, for example, following spousal heart attack, or bereavement (e.g. Hallaråker et al., 2001; Balaswamy et al., 2004);
- improved marital relationships (e.g. O'Connor et al., 2008);
- reduced caregiver burden and isolation (Love et al., 2005);
- improved subjective wellbeing and happiness among caregivers (Gray and Pattaravanich, 2019)
- more positive experiences of rehabilitation for both caregiver and care recipient (Lou et al., 2017)
- reduced mortality or increased survival (e.g. Aizer et al., 2013).

With regards to the latter point concerning the benefits of social support to survival, the classic findings of Berkman and Syme's nine-year follow-up study of 7,000 Californian residents with mixed health have been confirmed in many more specific populations (see Taylor 2004 for a review). More recently, Aizer's study of survival among over 734,000 American cancer patients found a consistent association between being married and surviving one's cancer, even after adjusting for demographics, cancer type and stage, and treatment provided (Aizer et al., 2013). The protective effects of marriage on health and health outcomes have been reported elsewhere, and generally point to greater 'gain' to husbands from wives' support during times of stress than married women seem to benefit from husband support (e.g. Cutrona, 1996).

Consensus exists that it is not simply the absolute number of supports a person has available to them (structural) but the perceived quality and function of these supports (functional), whether support is provided willingly or reluctantly (e.g. Williams et al., 2014), and satisfaction with the received support that is critical in predicting such outcomes although as noted below social support is not always received as helpful, even if intended as such by the caregiver.

Providing support to another can be considered a *prosocial behaviour*, with its characteristics of love, empathy, trust and altruism. The presence of the hormone **oxytocin** which acts on the peripheral and CNS and thus our behaviour, is influenced by our genetic make-up. It may be that those individuals who are willing to provide support to others differ in their oxytocin levels to those who are unwilling (Israel et al., 2012). This has been described by some as variations in 'tend and befriend' characteristics (e.g. Taylor, 2006, see Chapter 12 ☛) and certainly it opens up an interesting line of research – are we genetically predisposed to the caregiving role – is there a 'neurogenics of niceness' (Poulin and Holman, 2013; Poulin et al., 2013, and see Chapter 12 ☛). It is, however, unlikely to be the only explanation.

### Helpful and unhelpful caring

Studies of caring for people with a range of illnesses have found that there are common caring actions that are perceived as helpful – such as practical assistance and expressions of love, concern and understanding – and relative consistency in terms of actions considered to be unhelpful – for example, minimising the situation, ignoring the patient, being unrealistically cheerful, underestimating the illness effects on the patient, or being insensitive, critical or over-demanding. Among

oxytocin

this hormone which also acts as a neurotransmitter in the brain appears to attenuate (reduce) autonomic stress responses and may be associated with affiliative social behaviour young adults with cancer for example, friends distancing themselves or expressing pity were considered unhelpful (Breuer et al., 2017), in contrast to supporting them by being physically present and treating them 'as normal' (Woodgate, 2006).

Patients who perceived their support network or caregivers' actions as unhelpful have been found to have more negative perceptions of themselves and their spouses, and greater anxiety and depression (Clark and Stephens, 1996; Romano et al., 2009; Band et al., 2015). Furthermore significant others' beliefs have been found to affect their caregiving behaviours and care recipient outcome, as seen for example, in Band's systematic review of fourteen studies of the responses of significant others to chronic fatigue syndrome in a loved one. Making internal (to patient) attributions of cause and responsibility for the illness and its symptoms was found to be associated with unhelpful caring responses, such as forced cheerfulness and encouraging the patient to rest (both typically found to be unhelpful to patient outcome), and with both caregiver and patient distress.

Although helpful actions have generally been shown to occur more frequently than unhelpful actions, unhelpful actions appear to have a more strongly negative effect on wellbeing than helpful actions have a positive effect (e.g. Norris et al., 1990). Additionally, over caring or being overly helpful and solicitous (e.g. taking over a person's chores, encouraging them to rest) can act as a form of operant conditioning in which patients are rewarded for exhibiting 'sick role' behaviour (see Chapter 1 ☛) This can be seen among a sample of 119 patients with chronic fatigue syndrome and their significant other, where 'over-helped' care recipients exhibited greater fatigue and pain than those receiving punishing (e.g. caregiver expresses irritation at patient) or distracting (e.g. caregiver involves patient in activities) caregiver responses (Schmaling et al., 2000). Such findings have been confirmed in a review of studies within chronic fatigue syndrome, whereby 'over-helped' care recipients reported more severe and frequent symptoms and increased help-seeking behaviour (Band et al., 2015). Over-protected patients may also experience reduced perceptions of self-efficacy, self-esteem and recovery motivation, and elevated depression (e.g. Thompson and Pitts, 1992) and, among pain patients, increased disability (e.g. Williamson et al., 1997).

These types of findings highlight the need to assess positively perceived support separately from negatively perceived support, rather than assessing on a continuum of overall support without addressing how that support is evaluated. Given the evidence as to the presence of helpful and unhelpful caring actions, it is not perhaps surprising that, when initially faced with a caring role, care providers ask themselves questions such as, 'What is "good" care?' 'Am I suitably equipped to deal with the demands of the person I am caring for?' In some conditions, for example, multiple sclerosis, each new symptom or change in the affected person's functional ability can present family carers with new challenges, new emotions, and thus carers also need support to be effective and helpful carers (McCabe et al., 2014). As noted by Hauken and Larsen (2019) unhelpful support is typically inadvertent (not intended as such) and is often due to a lack of understanding or knowing what to do (rather than to a lack of care for the sick person) and in part this can be because the care recipient does not express to their support persons what they would find helpful or not, out of a reluctance to be a burden or from a desire to retain independence.

In an interesting study, Neff and Karney (2005) explore the widely held assumption that women are better at providing support than men, a conclusion drawn in part from the aforementioned findings that married men benefited more from marriage than do women. Using both observational data and seven-day diaries obtained from 169 newly married couples without children, the authors concluded that it is not that men and women differ in the skills of giving support to their partner, or even in the amount of support provided day to day, but that women are more responsive to the changing needs of their husbands as indicated in their stress-indicative behaviours and therefore provided better and more positive support at times of greater need.

## Consequences of caring for the caregiver

Unlike motherhood, a responsibility generally signalled by an expected event – childbirth – the informal caregiving role in the context of illness and disability is often one which emerges either suddenly or gradually but often unexpectedly out of a familial relationship. Like motherhood, however, there is generally little training for this role (Montgomery and Kosloski, 2000)! As noted by Kalra et al. (2004: 1,099) in relation to stroke management: ‘Although the physical, psychological, emotional, and social consequences of care-giving and its economic benefit to society are well recognised, caregivers’ needs are often given low priority’. Addressing caregiver needs is crucial to both patient and caregiver outcomes.

Providing care for, or helping others in an altruistic manner, for example through voluntary work, has generally been associated with social, emotional and possibly physical wellbeing of the helper, particularly among older adults (e.g. Post, 2007; O’Brien et al., 2011). However, providing regular care in the context of illness in a loved one has been seen more often as a threat to wellbeing, possibly because of the emotional bonds that exist or because familial carers do more than just provide ‘active help’ on occasion, and instead are immersed in the role 24 hours a day (Poulin et al., 2010). Many different terms have been used to describe caregiver outcomes of providing care, and just as many different outcome measures are used, some of which assess mental health, some physical health and some global psychosocial wellbeing. A commonly employed term is that of ‘caregiver burden’, defined as the objective and subjective ‘costs’ of caring to the caregiver (e.g. Zarit et al., 1980). This term covers a multidimensional outcome of caring that encompasses physical, psychological, financial and social costs of caring, and many studies have explored burden as an outcome, rather than focusing solely on emotional distress or physical outcomes (see review by van der Lee et al., 2014). In van der Lees’ review the behavioural problems of the care recipient, caregiver personality (particularly neuroticism) and coping responses, and caregiver competence (self-efficacy) were consistent determinants of caregiver burden. Similar determinants were found for depression.

## Emotional impact of caring

Research has typically found care-givers for someone with chronic illness or disability experience significant distress at a level significantly higher than that found in age-matched controls (Pinquart and Sörensen, 2003). Similarly, caregivers’ physical health and life satisfaction are generally found to be lower than in non-caregivers (e.g. Schulz and Sherwood, 2008; Bergland, Lytsy and Westerling, 2015). Bergland’s study involved almost 90,000 members of the Swedish general public and compared the 11 per cent who were caregivers with those who were not – they find significantly increased odds of both poorer self-rated health and lower psychological wellbeing. It is important that comparative data is examined – many of the studies report only data from a carer sample, which makes it impossible to conclude whether the caregiver experience is different from the general population. See Table 15.2 for some common causes of caregiver distress.

Studies suggest that emotional distress is most marked among women caregivers (e.g. Kuenzler et al., 2010; Pinquart and Sörensen, 2003; van den Heuvel et al., 2001), although some of the reported gender differences may relate to gender imbalance in study samples. As described earlier, the type of care task typically performed by male and female caregivers may also differ, with some evidence that the provision of personal care (dressing, bathing, toileting, feeding etc), more typically provided by female caregivers, is more emotionally demanding and/or physically draining. This could be due in part to the general time urgency of these kinds of tasks, and/or to the level of intimacy involved in providing them.

In relation to caring for a sick child, it has also been suggested that fathers are less distressed by caregiving than are the mothers (above and beyond any gender effect on distress in general non-caregiving populations, see review and meta-analysis of Pinquhart and Sorenson 2006), although differences do not appear huge. For example, 51 per cent of mothers and 39 per cent of fathers exhibited levels above the cut-off for emotional disorder in a study of parents of a child with cancer, and for both

**Table 15.2** Potential causes of caregiver distress

- The financial drain of caring caused by caring interference with employment
- The emotional demands of providing long-term care for a relative who often provides little in return
- The physically tiring nature of some caring roles
- The inability to replenish personal resources due to social isolation or poor utilisation of support resources and leisure time

Or more deep-seated, even unacknowledged sources of stress:

- Feelings of anger or resentment (e.g. with the person for becoming ill, for them being born handicapped)
- Feelings of guilt (e.g. that they may have directly/indirectly contributed to the situation)
- Feelings of grief (e.g. that they have ‘lost’ who they used to have)

These latter are indicative of extremely complex feelings that are difficult to voice, but if they are suppressed they can cause increased stress and distress.

parents distress remained high even after cancer treatment had been completed, reflecting parental fears of recurrence (Sloper, 2000). We raise the issue of whether masculine identity influences the appraisals men make of the caring role and their experiences of the role, in a later section and in 'In the spotlight'.

The life stage of a caregiver may influence the emotional experience of caregiving, for example still being at school, attending Higher Education, being in employment, or being retured. One example of the feelings of young carers comes from a qualitative interview study of those aged 14–18 years (Bolas et al., 2007) where feelings of isolation were reported. This isolation was considered to arise from their not discussing or concealing their role so they were not seen by peers or social contacts as being 'different', or to avoid any stigma attached to the illness (more likely if their care recipient was suffering from a mental health condition). Although the young carers also reported positives in terms of enhanced self-regard and self-esteem, and pride was taken in performing caregiving tasks and feeling useful, such gains may not outweigh the negatives – unless, as one carer stated, they put this experience to good use in a future career as a carer for others. This isolation has clear implications for their own emotional wellbeing. However it is not just young carers that report isolation from not disclosing their caregiving role- working male carers have been found to be less likely to tell their employer of their other role than working female carers, thus they miss out on potential support, including flexible working etc. Worryingly some studies find a lack of disclosure is due to fear of workplace discrimination (Maynard et al., 2018).

In a study of 442 carers aged under 16 years in Ireland (Cassidy et al., 2014), 36 per cent were found to exhibit clinical levels of distress (as assessed using the recommended caseness cut-offs of the General Health Questionnaire). Negative mental health was predicted by appraisals of burden, stress appraisals and benefit-finding (discussed in detail below). Low levels of support from family and friends, low levels of problem-focused coping and low levels of social recognition for their role were also predictive although these effects disappeared when all other variables had been entered into the analysis. However, it was clear that negative mental health effects were present, and yet, surprisingly, these effects were not mediated by the young caregivers' resilience or, in other words, their ability to 'bounce back' from stress. We have previously described the importance of personal resilience to coping with stress (see Chapter 12 ☛).

Young adults, aged 18–25 years also report challenges of caring, when perhaps entering into other commitments such as Higher Education, employment, or other roles concomitant with a life stage of increased autonomy and maturity (see Chapter 1 ☛). Haugland and colleagues, (Haugland, Hysing and Sivertsen, 2020), in a national survey of over 40,000 university students, found that 5.5 per cent had caring responsibilities, and among those there were a greater prevalence of mental health problems, somatic symptoms including insomnia, and a lower life satisfaction. The carers also were more likely to be female, single, and having financial difficulties. However the care recipients in this study could be 'family or other' and it is unclear whether the care role could include paid work.

## Physical effects of caring

The stress of caring may also impact on some, but perhaps not all, people's physical health, ranging from sleep and weight disturbance (Klassen et al., 2012, through increased risk of physical health complaints (Kiecolt-Glaser et al., 2003), to actual health complaints such as back or joint pain (Triantafillou et al., 2010). Among cancer caregivers, for example, female caregivers experienced a decline in their own physical health in the six months following their partner's diagnosis of colorectal cancer, whereas male caregivers did not (Nijboer et al., 2001), perhaps relating to the higher levels of distress or lower levels of caregiver-perceived efficacy reported among women caregivers in other studies, although this study did not explore these issues. Interestingly, an extremely large study of the physical health, psychological well-being and quality of life of over eleven thousand Australian women aged from 70 to 75 (Lee, 2001) did not find a significant difference in physical health between the 10 per cent identified as care-givers and the majority of the elderly sample. However, the caregivers did differ significantly in terms of their emotional wellbeing and perceived stress levels, supporting the reasonably consistent findings as to the emotional impact of caring (see below). Wider quality of life is also affected, encompassing physical, social and emotional domains, for example. In the EUROFAMCARE study addressing carers in six European countries (as described earlier), carers in the UK and Sweden reported the highest quality of life (65 per cent and 67 per cent respectively), while those in Greece and Italy reported the lowest (50 per cent and 51 per cent respectively), which has been tentatively attributed to greater availability of services and active carer policies in the former countries (as cited in Triantafillou et al., 2010).

## Immunological effects of caring

As described in Chapter 11 ☛, the nature, intensity, duration and frequency of stressor events have been found to influence the nature and extent of immune change in a dynamic manner, in part dependent on the state of the immune system at the time the stressor event occurs (Dantzer and Kelley, 1989). There is a large body of evidence that points to immunosuppressant effects of long-term caring, and the effects can be exacerbated in older adults who may have pre-existing immune weaknesses (Graham et al., 2006, and see Chapter 12 ☛). In relation to caregiving stress, while immune effects are seen consistently in studies of older caregivers, findings among younger populations have been more inconsistent. For example, elderly caregivers of a spouse with Alzheimer's disease had lower immune function and reported more days of illness over the previous year than similarly aged healthy control subjects (Kiecolt-Glaser et al., 1994), and the immuno-compromising effects of caring for a person with Alzheimer's has generally been confirmed (see reviews by Bourgeois et al., 1996; Kiecolt-Glaser et al., 2002). For example, Kiecolt-Glaser et al. (1996) conducted an early study where caregivers were given an influenza vaccination, and showed less appropriate immune responses to the vaccination than did the well-matched control participants. Differences were particularly evident when comparing those aged over 70 years (23.3 per cent of caregivers responded to the vaccine, compared to 60 per cent of controls) compared to those younger than 70 years (53.8 per cent of the caregivers responded compared to 70 per cent of the control subjects). Vedhara et al. (2002), however, found that caregivers of a spouse with multiple sclerosis did not differ in their immune responses following an influenza vaccination from non-caregivers. Multiple sclerosis is a condition equally as chronic as Alzheimer's but affecting a younger population, thus spousal caregivers are generally younger than spousal caregivers in the dementias. Vedhara's sample of younger caregivers did, however, also appear to be less distressed about their caring than that reported among other caregiver groups, which may in part explain their 'preserved' immune responses following vaccination. In another younger sample, parents of young children with a developmental disability, a reduced immune response both to influenza and pneumococcal vaccination was found, when compared to sex- and age-matched controls. In this study the reduced response to vaccination was greatest when parents were experiencing greater problem behaviours from the child (Gallagher et al., 2009a, b). Together these findings suggest that immune responses to caregiving exist but that they may vary across populations and conditions, and that other factors are also likely to be at play.

An important point is that research into the physical consequences of carer stress have generally examined and found evidence of increased vulnerability to disease resulting from immune changes rather than actual disease development: for example, raised levels of the pro-inflammatory cytokine interleukin-6 found among caregivers is at a level considered a risk factor for cardiovascular disease (Kiecolt-Glaser et al., 2003). As described in Chapter 11 ☛ life stress has been shown to influence various inflammatory and immune responses (for example, the concentration of C-reactive protein and interleukin-6), with suggestions of these processes accelerating the development of age-related diseases (see Chapter 12 ☛). Kiecolt-Glaser and colleagues (2011) have also therefore examined the relationship between caregiving stress and the possibility of accelerated ageing by means of assessing telomere length – shorter **telomeres** had previously been associated with higher IL-6, and tumour necrosis factor-alpha (TNF-a) (Epel, 2009). In their sample of Alzheimer's caregivers compared to controls (mean age 69.7 years overall), they found that caregivers had significantly shorter telomeres than controls. Furthermore, controlling for caregiver status and other relevant factors, the experience of multiple early-life adversity was associated with higher IL-6 and shorter telomeres, which they claimed could translate into a five–seven year difference in projected lifespan. Caregiving further magnified some of these relationships, reflecting the potential additive effects of stress.

In spite of the negative aspects of caring, studies have increasingly asked whether there are also positive aspects of the caring role.

**telomeres**
DNA clusters on the tip of our chromosomes, which prevent the DNA unravelling; telomeres shorten naturally with age to the point where the cell cannot replicate

### Positive aspects of the caring role

Orbell et al. (1993) noted that caring 'may be appraised by the caregiver as negative, benign or positive. Caring may be appraised as an intrusion on personal lifeplans, but may also be appraised as positive, to the extent that it provides affirmation of valued aspects of the self' (p. 153). There are many reports of subjective feelings of satisfaction and rewards arising from the care role. For example, studies have identified caring satisfaction such as feeling a sense of fulfilment, feeling useful, increased feelings of closeness or increased day-to-day interactions as a result of patients and caregivers spending more leisure time together (e.g. Kinney et al., 1995; Kramer, 1997; Parveen and Morrison, 2012), and greater empathy and compassion among child caregivers than non-care-giving peers (Charles and Marshall, 2012). In an early study, Kinney et al. (1995) investigated the daily hassles and uplifts (stresses and satisfactions) reported by 78 family caregivers of stroke patients and found that caregivers generally reported more uplifts (such as the care recipient cooperating with them, having pleasant interactions with care recipient) on a day-to-day basis than they did hassles (such as care recipient complaining or criticising, care recipient being unresponsive). However, this varied depending on the care recipient's level of impairment, with care recipients who had greater impairment generally having caregivers who reported more hassles. While hassles predicted poor caregiver wellbeing, when the overall number of uplifts outweighed the number of hassles, caregiver outcomes were improved (less depressed, better social relations). Such protective or buffering effects of uplifts, even in the face of concurrent hassles, highlights the importance of assessing both negative and positive aspects of caring and the interaction between them. Rapp and Chao (2000) in their study of dementia caregivers concluded that appraisals of strain and appraisals of gain exerted independent effects on negative affect (strain positively associated with NA, gain negatively associated). Interestingly, neither gain nor strain was associated with positive affect, which points to the fact that many factors influence caregiver affect, not only their appraisals of gain or strain. In a child caregiver sample, Cassidy et al. (2014) found that benefit-finding was explained primarily by perceived support from family and friends, and also by low perceived stress, the use of problem-focused coping, perceived social recognition of their role, and personal resilience. In turn, benefit-finding was associated with positive outcomes, as supported by longitudinal studies.

Furthermore, a review and reappraisal of the caregiving literature has led to questions as to whether caregiving is as generally negative as we have long supposed. This timely review in fact suggests that the positive experiences of caring have been downplayed, including longitudinal evidence from five large cohorts of caregivers and non-caregivers where a significant survival *advantage* has been found for caregivers (Roth et al., 2015). Such findings hold important implications for the future in terms of changing the population's expectations of taking on a caring role, and potentially enhancing willingness to take on the role if required. Nonetheless, whether outcomes are positive or negative, understanding is needed of the factors that act to increase or decrease the benefits of caregiving experienced.

## Influences on caring outcomes

### Features of the illness or of the cared-for

The illness or behavioural features of the care recipients have important but complex influences on caregiver outcome. Studies of caregivers of people with Alzheimer's disease, for example, have shown that distress is more clearly associated with demanding or disruptive behaviour than with the level of physical impairment or disability of the care recipient (e.g. Morrison, 1999; Gaughler et al., 2000). Caregiver distress is subject to further fluctuations dependent on the care recipient's physical and mental wellbeing at any point in time (e.g. Beach et al., 2000).

Among caregivers of stroke survivors, while the severity of stroke impairment during the acute phase (i.e. approximately ten days post-stroke) predicted their future expectancies, it was their appraisals of the consequences of the illness and of their own coping resources that predicted their psychological wellbeing (Forsberg-Wärleby et al., 2001). The caregiver's subjective appraisals of the situation therefore differ from objective features of the illness including disability severity, in the extent to which they determine caregiver outcomes. To illustrate this further, again among those caring for stroke survivors, depression at six months was predicted primarily by an increase in negative characteristics of the care recipient (such as demanding behaviour), by reductions in caregivers perceiving that they had a reciprocal confiding relationship with the person they cared for, by the age and health of the care recipient (but not the caregiver's own age and health), and by income and a change in living standards. In contrast, caregiver burden was explained by the age of the caregiver (older caregivers were less burdened), a decline in the positive characteristics of the care recipient, reduced satisfaction with their own social contacts, and increased concern for future care (Schulz et al., 1988). This study, while somewhat dated, remains important because it examined changes in objective and subjective predictor variables over time, reflecting how the demands of caring are dynamic and fluctuating. It is worth noting that an increase in negative characteristics of the care recipient predicted caregiver depression, whereas a decrease in their positive characteristics predicted caregiver perceived burden. This reflects that burden is not equivalent to depression (as some studies imply) but is perhaps more tied up with the relationship between the caregiver and care recipient. It is increasingly evident that adjustment on the part of the caregiver (as well as the patient's own adjustment) is influenced by interpersonal processes, and, in the case of couples where one has an illness, the emotional, cognitive and behavioural responses of both parties to the situation. We address such dyadic factors in a later section.

## The influence of caregiver characteristics and responses

### Ethnicity and culture

Rapp and Chao (2000) found that the reported benefits of caregiving for a spouse or parent with dementia were greater in their small sample of Black caregivers than their larger sample of White caregivers, which may reflect strong values around familism and filial piety (Tang, 2006; Feng et al., 2013), or possibly differences in the willingness of caregivers of different ethnicities or different cultural affiliations, to seek support outwith the family. Katbamnna and colleagues (2004) found that the fear of obligation to others reduced the likelihood of South Asian family care-givers making use of a wider social network to help provide care. This study did not find evidence of the oft-assumed willingness of extended family members to support the primary caregiver, for example Gray and colleagues point to such connectedness being a central cultural value (Gray et al., 2016, as discussed elsewhere with regards to collectivism). Most other studies support this: for example, in a review of 20 years of caring research, minority caregivers more often included extended family members than did White caregivers (non-Hispanic) (Dilworth-Anderson et al., 2002); in the UK, higher levels of familism (feelings of loyalty and solidarity among family members, related to providing care) were found among British South Asian caregivers compared to White-British caregivers (Parveen and Morrison, 2009); and familism was found to be higher among African American, Asian and Latino caregivers compared to White caregivers (e.g. Knight et al., 2002). A study of South Asian caregivers living in Canada and providing care for their child with cancer (Klassen et al., 2012) provides qualitative evidence of distress compounded by a lack of support – consider this quote from a mother.

'I think I didn't deal with it too well at that time. That depression continues to this day . . . My depression kept getting worse. I was alone . . . I used to sometimes wish to tell more people, but my husband said, 'That won't be good, because the more you repeat these things to people, the more you'll think about them' (p. 7).

Further ethnic variations found in terms of coping strategies used and caregiving outcomes, were reported by Parveen and colleagues (Parveen et al., 2013), whose findings highlight the importance not assuming that models of illness cognition and coping hold for all cultures or even microcultures. Drawing from the only theoretical model within the caregiving literature which explicitly considers the role culture plays in the stress-coping-outcome relationship – (The Sociocultural Stress and Coping Model, Aranda and Knight, 1997; Knight and Sayegh, 2010), Parveen reports differences between White-British and British South Asian caregivers. There was no effect of caregiver relationship type (spouse, adult child (or child in-law) and others (parents or siblings)) on the mood of White-British caregivers, but among British South Asian caregivers, spousal caregivers were both less anxious and less depressed than the adult-child or other type of caregiver. Similarly being married, compared to a group comprising single, divorced or widowed individuals, was associated with less anxiety and depression in the British South Asian sample but made no difference to the mood of White-British caregivers. Finally, the mood of the British South Asian caregivers was not affected by the diagnosis of the care recipient whereas among White-British caregivers those providing care for a loved one with dementia had significantly higher anxiety than caregivers in Parkinson's disease, MS, dementia or other diagnoses, and significantly more depression than Parkinson's disease, MS, cancer or other caregivers. Beliefs differed- controlling for the effect of age (as British South Asian caregivers were younger), British South Asian caregivers had significantly higher levels of familism – although contrary to expectations this was not significantly associated with mood. Perhaps as a consequence of different beliefs, although this was not fully tested, coping also differed, with British South Asian caregivers using significantly more behavioural disengagement and religious coping and reported significantly less support than White-British caregivers. In addition in this study, while levels of willingness to care did not differ between the two caregiver groups, willingness to care and caregiver anxiety were related in opposing directions. Highly willing South Asian caregivers were more anxious, and highly willing White-British caregivers were less anxious. The authors suggest that this may be due to South Asian caregivers' willingness to care being related to the fulfillment of culturally valued obligations to care, thus leading to anxiety about failing to fulfil such obligations, whereas White-British caregivers were perhaps willing to provide care for more intrinsic reasons, including personal choice (Parveen et al., 2011).

In an interesting and rare study of American Indian caregivers (Goins et al., 2011) highlights that few studies actually assess 'culture' in terms of the extent to which individuals identify with, and value, their own minority culture (reflected in use of their own language, rituals, or healing traditions, for example) as opposed to that of the dominant culture. Ethnicity is not the same as culture and it is important that caregiving research recognises that cultural identity may vary within those of a shared ethnicity, and therefore exert different influences on response to, and outcomes of, providing care.

## RESEARCH FOCUS

### Resilience and young carers

Wepf, H., Joseph,S. and Leu, A. (2021). Benefit finding moderates the relationship between young caregiver experiences and mental well-being, *Psychology & Health*, doi: 10.1080/08870446.2021.1941961

### Introduction

As described earlier in this chapter, young carers may be prone to particular challenges of caregiving in terms of implications for their schooling, their social participation and friendships, and for some, fear of stigma which may limit their disclosure to possible sources of support. Post-traumatic growth and benefit finding have been reported among predominantly adult studies, but also among studies with adolescents caring for parents with a range of health conditions, with evidence of benefits to indicators of positive adjustment including reduced distress, adaptive coping and a better quality of life (e.g. Cassidy, Giles and McLaughlin, 2014; Pakenham and Cox, 2018).

What is less often studied is the nature of the benefits experienced, although some authors have described six dimensions – that of *acceptance* (e.g. accepting things, taking things as they come, adjusting to things that can't be changed), *family bonds* (appreciating family more, being more sensitive to family issues, being closer), *relationships* (being aware of support from others, feeling positive about others, realising who real friends are), *growth* (coping better, being stronger, being more effective, handling things), *reprioritisation* (deemphasising material things, living more simply, changing priorities and *empathy* (being more compassionate to others in similar situation, caring about others, being sensitive to others' needs) (Cassidy, McLaughlin and Giles, 2014). Furthermore studies have addressed benefit finding in caregiving youths but without a comparator of how these same individuals respond to general life stress, nor do studies often compare their findings with non-caregiving youth. This study seeks to address this limitation.

### Aims and objectives

The study aims to generate new understanding of positive outcomes in young carers by addressing the following questions:

1. Is there an association between being a young carer and degrees and profiles of benefit finding in response to life stress?
2. Does benefit finding in response to life stress moderate the association between having caring experiences (yes/no) and mental wellbeing in adolescents?

To address these questions the study first compares benefit finding scores in response to general life stress between the two groups – carer and non-carer peers; using Cassidy et al.'s (2014b) dimensions.

Secondly, they examined whether the association between having caring experiences or not and mental wellbeing differed depending on overall levels of benefit finding (and the different dimensions).

Participants included 2525 adolescents attending school or vocational training in Switzerland (interestingly aged 15–21 years, thus a high cut-off for adolescent and more typically the 18–21s may be described as 'young adults'). The questionnaire administered took approximately 25 minutes to complete and assessed:

- caring experience (providing care for a family member or close friend with a need for support caused by health problems (yes/no), and if 'yes', extent of help, frequency of four categories of care tasks-domestic/household care; intimate care; social/emotional care and instrumental care, and an indication of whether this was current or past;
- adverse life events (a checklist of 26 events based on pre-existing adolescent assessment tools and concerning, family events, school or career events, and personal events);
- benefit finding was assessed using Cassidy et al.'s (2014b) 28 item General Benefit Finding Scale where participants indicate the presence and extent of benefit (using the six subscales described above) felt in relation to past difficult times they had experienced;
- mental wellbeing was assessed using the German version of the Warwick-Edinburgh Mental Well-being Scale.

## Results

Results were compared between a 'young carer' group comprising of 1,137 adolescents providing some type of care currently (n = 601, mean age 17.87, 72 per cent female) or previously (n = 536, mean age 17.81, 56.5 per cent female), or 'without caring experiences' (n = 1,388, mean age 17.63, 55.5 per cent female). Detailed results can be found at source, but a key point summary is that:

- The young carer group had significantly higher overall benefit finding overall, and specifically growth and empathy, even when controlling for the number of adverse life events.
- Regression analyses found that young carers who identified benefits of their caring role had greater overall benefit finding, relationship benefit and empathy, than those that did not and whether current or former carer did not affect this.
- Testing the moderating effect of benefit finding in the relationship between caring experience and wellbeing, hierarchical regression analysis found that the effect of having caring experience on mental wellbeing was only negative when adolescents had a low level of benefit finding.
- Among young carers overall benefit finding as well as the relationships and growth subscales were positively associated with mental wellbeing, and interestingly empathy benefit was negatively associated with wellbeing.
- The positive association between relationship benefit finding and wellbeing existed for the combined sample overall, and for those young carers who related their benefit finding to caring.

## Discussion

This well written and succinct paper confirmed their hypotheses in that a) being a young carer did relate to benefit finding, and that those who linked benefits to caring recorded overall higher levels of benefits, empathy and improved relationships, and b) benefit finding moderated the negative association between caring experiences and mental wellbeing.

However sometimes what is important in research is what was *not* significant (remember that when you start to feel depressed in your undergraduate projects when your hypotheses may not be supported by your statistics!). In this study only a couple of the benefit-finding subscales emerged as significant – relationships, growth, and empathy, but not family bonds,

*(continued)*

acceptance or reprioritisation. Furthermore while certainly personal growth, as seen in feelings of increased self-confidence and inner strength, and relationship benefits look favourable for wellbeing, empathy worked in the opposite direction! Perhaps for young people over-identification with others needs is unhelpful to their emotional wellbeing- the authors do not spend a lot of time speculating on this but this issue is worthy of further exploration as generally empathy is viewed as a positive quality, an indicator of emotional intelligence even, but at what point does it become unhelpful- does it impede one's day to day function by creating worry perhaps? It would be nice to see this examined in both young carers, but also older carers – I personally wonder if empathy may be associated with rumination, which as we describe elsewhere in this textbook, has been associated with negative mood.

Overall this paper concludes by highlighting the value of comparing carers (current and past) with non-carers, and other strengths and limitations. Apart from the usual point about cross-sectional design limitations, one issue worth highlighting is their sampling by virtue of potential participants being 'adolescent', as opposed to sampling from those identifiying themselves previously as carers. While this is more inclusive, i.e. not all people doing caring tasks would label themselves as 'carers' as we described earlier in this chapter, and may not have responded to a study advertised as such, it does however mean that the current samples responses may not be directly comparable to those coming forward to studies who *do* self-identify as a carer explicitly.

Limitations aside, this paper is a good read and addresses an important question that holds implications for how we/professionals work with young carers. It also examines the type of benefit more closely than many other studies and this enables even more targeted intervention, and thus it is worthy of this Research Focus- I hope you agree!

## Personality

Studies have highlighted the role of caregiver personality variables such as optimism (generally a positive resource) and neuroticism (generally a negative characteristic), showing that these characteristics had direct effects on caregiver mental health, as well as indirect effects via their influence on perceived stress, and on the perceptions and appraisals of the care recipient's level of impairment (e.g. Hooker et al., 1992; Shifren and Hooker, 1995). More recently, a review of caregiver burden in dementia found that caregiver neuroticism was significantly associated with caregiver burden and depression (Van der Lee et al., 2014).

Research interest has also turned to the more positive construct of resilience – the ability to 'bounce back' in times of adversity, (Werner and Smith, 1992), thought to be either a fixed trait or a stress-invoked adaptive response (Smith, 2006) (see also Chapter 12 ☛). Cassidy et al. (2014), in their study of child caregivers, found that resilience was a small but significant predictor of life satisfaction and positive mental health (four and three per cent of the variance accounted for respectively), whereas resilience did not predict negative mental health and only explained one per cent of the variance in benefit-finding. It may be that, as these authors conclude, resilience is more important for developing positive health outcomes than it is for reducing negative outcomes.

## Attachment

Pietromonaco et al. (2013) highlighted a need for health psychology research, particularly that attempting to understand processes of adjusting to illness within families, to better integrate relationship science and, in particular, attachment theory (cf Bowlby, 1969, 1973). Attachments formed in childhood between a child and a parent (four protypical styles derived from two dimensions – anxiety and avoidance) are also seen in adult intimate relationships, and likely to be activated during periods of illness where one member takes on a caregiving role. Anxious attached individuals are governed by attending to distress and focus on their own distress and needs, with a fear of being rejected by others as a result of not being good enough. This anxiety is perhaps increased if the other person is absorbed in their own situation, such as is the case when a person is ill. Those with an avoidant attachment style, however, are characterised by a tendency to separate their thoughts from their emotions, and to be self-reliant to the point of emotional detachment from others as perhaps a form of self-protection (from potential distress). Illness in a loved one, with consequent needs for the partner to emotionally invest in providing care, is thought to create a type of distancing. *Secure* adults are low in anxiety and avoidance, *preoccupied* adults are high in anxiety but low in avoidance, *fearful avoidant* individuals are high in both anxiety and avoidance, and *dismissing avoidant* individuals are low in anxiety but high in avoidance (Feeney and Collins, 2001: 973).

A growing body of research has been testing these theories in caregiver samples where the caregiver is spouse-partner (rather than an adult caring for a parent where adult-child attachments are present). For example, studies with cancer caregivers have found that having a secure attachment was related to autonomous motives for caregiving and for benefit-finding (both discussed in previous sections) (Kim et al., 2008). Hasson-Ohayon and colleagues (2013) find an association between attachment style and finding meaning with an interesting gender difference – for men, finding meaning in caregiving was associated with low avoidance attachment, whereas for female caregivers finding meaning was positively associated with having social support. The authors propose that avoidant attachments may prevent those caregivers from accessing social interaction or, indeed, being emotionally involved in their caregiving role sufficiently to enable finding any meaning within it- this relates to earlier discussions of gender differences in communicating. In contrast, anxious attachment was not associated with finding meaning. Anxiously attached individuals by definition tend to be motivated more by addressing emotional needs and worries and therefore were hypothesised to experience more distress when required to take on the care of a loved one. This is supported in a study of cancer caregivers where an anxious attachment style was positively related to caregiver depression (Braun et al., 2007). Furthermore, among female caregivers of male partners admitted to hospital with acute coronary syndrome and assessed during the hospital stay and again six months later, there was a significantly stronger association between caregiver reported burden and depression in those with higher attachment anxiety (Vilchinsky et al., 2014).

## Caregiver appraisals

It is generally accepted that the underlying source of caregiver distress or strain appears to result from subjective appraisals of an imbalance between the demands of caring and the resources perceived to be available to the caregiver (e.g. Orbell and Gillies 1993), which may include what Wallander and Varni (1998) refer to as 'resistance factors'. Resistance factors include intrapersonal factors such as personality, motivation, and self-efficacy beliefs, socio-ecological factors such as the caregiver's family environment and support resources, and stress-processing factors, which include an individual's cognitive appraisals of a situation and their coping responses (akin to Lazarus's theory, Chapter 11 ☛ or Leventhal's common-sense model/self-regulation of illness model described in Chapter 9 ☛). The principles outlined therefore in earlier chapters hold here in the context of caregiving.

For example, perceptions of the illness itself, rather than perceptions of caregiving, played a role in the distress of caregivers studied by McClenahan and Weinman (1998) where caregivers who had a chronic perceived timeline for the illness showed greater caregiver distress. However, there is a larger body of work exploring the impact of carer illness perceptions on patient outcomes, as we also refer to when discussing dyadic beliefs later in the chapter, than there is currently in relation to caregivers' own outcomes.

Several studies point to a significant influence of caregiver perceptions of self-efficacy, i.e. the extent to which they feel equipped to carry out caregiving tasks, on emotional outcomes and perceptions of strain or burden (e.g. van den Heuvel et al., 2001; Chronister and Chan, 2006; Merluzzi et al., 2011). In this latter study, conducted within the context of palliative care, a care-giver efficacy inventory (CGI) was developed which produced four factors of perceived efficacy:

- in managing medical information;
- in caring for the care recipient;
- in caring for oneself;
- in managing difficult interactions and emotions.

In their study of 133 informal caregivers, the total CGI efficacy score was negatively associated with stress and burden, but in regression analyses the factors of caring for oneself and managing difficult interactions and emotions emerged as the most important to stress and burden. These are interesting findings worthy of further prospective examination and in caregivers of non-palliative populations where the need for carer self-care or the emotional experience may differ substantially.

There has also been a general finding for males, firstly to take on less of a caring role, and, secondly, for those that do become a caregiver, for them to experience it differently to women due to taking on a non-socialised and less valued social role. The evidence, however, is not so clear-cut as may be expected, nor is it clear whether males appraise the role differently to females – see 'In the spotlight'.

## IN THE SPOTLIGHT

### Masculinity and caregiving

Stereotypical views of male gender is that, compared to females, males are less empathic, exhibit fewer emotional responses and more instrumental or practical coping responses in times of stress. While gender is biologically determined, 'gender role' concerns issues of masculinity and femininity – identification of such are often socially determined (big boys don't cry, girls don't play with construction kits, etc., etc.), as defined by the World Health Organization (2014), where gender role concerns 'socially constructed roles, behaviors, activities and attributes that a given society considers appropriate for men and women'. It is expected that gender role expectations/norms therefore vary in different societies/cultures, and furthermore, as found in Pinquhart and Sorensen's (2006) review and meta-analysis, change over time as a result of social change, i.e. less gender variation in more recent studies compared to studies from earlier generations.

Gender role identity where measured, commonly categorised people on the basis of certain characteristics: e.g. masculine 'instrumental' traits include, for example, 'aggressive', 'dominant', whereas feminine 'expressive' traits include 'warm', 'sincere' (common scales used include the BEM Sex Role Inventory, Bem, 1979, and the Personal Attributes Questionnaire, Spence and Helmreich, 1978, cited in Baker et al. 2010).

Until recently, there has been little exploration of how these self-identified traits are associated with coping appraisals generally, or for current interests, in relation to caregiving processes and outcomes. Hoyt (2009) describes how the usefulness of emotional approach coping, or the expressing and processing of emotion, for men, is unclear, and likely influenced by the extent to which a male subscribes to traditional male beliefs, and roles or experiences conflict with these. In his study of men with cancer, i.e. *not* caregivers, high gender role conflict was indeed related to low levels of emotional expression and in turn (as well as directly to) higher levels of distress. Taking this into the arena of caregiving, feeling conflicted with traditional gendered roles may also influence a caregiver's use of social support. Supporting this, some working male carers have been found to be less likely to disclose a caregiving role due to fear of workplace discrimination (Maynard et al., 2018).

Compromised health has been shown to create role conflict, with illness described by some as a threat to masculinity (see Chapter 14 ☛), similarly therefore, such feelings arising from the socialised male role may influence how men adapt to providing care for a loved one at home, where social support may be needed but not sought.

In a study of husbands caring for their wives who had been diagnosed with dementia Baker et al. (2010) found that both 'Masculine' instrumentality and 'Feminine' expressiveness were significantly and negatively correlated with personal strain, and Masculine instrumentality was significantly and negatively correlated with care role strain. However, none of those relationships persisted in multivariate regressions and instead caregiver *role strain* was explained by caregiving situational characteristics (e.g. high duration of caregiving, negative reaction to recipients' memory and behaviour problems) Poor self-rated caregiver health also added significantly to the explanation of personal strain.

It is important also that studies explore the social-support-seeking behaviours that are associated with gender role beliefs as these may socially constrain coping behaviours and potentially adjustment to caregiving.

One final thought: Baker and colleagues intriguingly propose that there may be a response bias at play whereby men may report feeling strained as caregiver as a means of distancing themselves from a role they perceive as fundamentally a feminine role and thus one they shouldn't be competent at! Conversely of course they may not want to report they are not coping out of concern that they will appear 'not "man enough" for the job' (p. 325). To explore these interesting issues further we need more studies to examine the interaction between gendered identity and care role appraisals, coping responses and outcomes and, ideally, also explore any perceived pressures or influences on reporting.

As described in Chapter 12 ☛, while perceiving control over outcome may not be always realistic, finding or retaining control over some aspects of an event or one's responses to it has generally been shown to be beneficial (Hagedoorn et al., 2002; Montpetit and Bergman, 2007). Among married couples, it has even been shown that spouse caregivers' confidence in the recovery of their spouse following a stroke (Molloy et al., 2008), or in the patient's own self-efficacy for managing their condition (arthritis, Gere et al., 2014) can be a significant longitudinal predictor of patient outcomes. However, what effect do such beliefs have on carers' outcomes?

One example, Hagedoorn et al. (2002), in a comparison of male and female caregivers of a partner with cancer, found that elevated distress among female caregivers was found only in those who reported low levels of caregiver efficacy (not believing in one's ability to care effectively) and perceived challenges to their role identity resulting from a perception of not 'caring well'. Another study of cancer caregivers, however, found that perceived control over caregiving demands did not predict outcome, positive or negative (Fitzell and Pakenham, 2010). They assessed caregiver appraisals of demand (stress, challenge) and resources (personal control, social support) in relation to both positive and negative caregiver adjustment, and while perceived control was not predictive, perceived stress (assessed using a single item) was. Perhaps surprisingly, scores on the more robust five-item measure of perceived challenge was predictive only of life satisfaction, illustrating that 'stress' is about more than just challenge – and indeed, the 'resource' variable of satisfaction with social support also added significantly to the prediction of all outcomes. The authors suggest that the lack of prediction of control beliefs (and also in fact of most of the coping subscales they assessed) may be due to using items which referred to control over caregiving challenges generally, rather than specific demands/caregiving tasks. This issue of whether to assess generically or specifically is an important one which we have addressed at various points throughout this text.

## Use of social support

Shewchuck et al. (1998) found that adjustment to caring for a person with a spinal cord injury varied significantly over the first caring year and was influenced by patient and caregiver characteristics, such as age, the caregiver's own health, and also by the caregiver's behaviour in terms of their use of support. Using social support as a coping strategy has emerged as an important predictor of caregiver outcomes. For example, in a study of male heart attack patients and their spouses, Bennett and Connell (1999) found that the primary causes of care-giver anxiety were the perceived consequences of the heart attack, with many wives becoming hyper-vigilant, watching for signs that their partner may have a further MI, and that the lack of a confidante with whom they could discuss these concerns was an important factor in maintaining anxiety. Perceived social support, or the lack of it, also played a central role in the stress process model predicting QoL or burden in caregiving for a family member with traumatic brain injury (Chronister and Chan, 2006). Following a longitudinal study of 88 couples where one partner has colorectal cancer, Hagedoorn et al. (2011) report findings whereby if past (pre-cancer) spousal support was perceived as being high, both patients and partners rated the quality of their relationship relatively high, regardless of their spouses' current supportive behaviour. Although the measure of spousal supportiveness relies on retrospective reports of pre-cancer behaviour and thus may be prone to bias, such findings highlight the importance of having a supportive 'history' even if current support is less good – perhaps attributions for current low levels of active engagement or high levels of protective buffering are more sympathetic or more externally attributed, thus allowing relationship satisfaction to be maintained.

## Protective buffering

Other caregiver behaviour, such as that made in response to the patient's situation, may also influence their emotional wellbeing: for example, spousal caregivers have been found to inhibit, deny or conceal negative information, thoughts or feelings, and yield to partners, in order to 'protect' their partners, although in doing so they may increase their own distress and even that of the patient partner (e.g. wives of heart attack patients, Coyne and Smith, 1991; spouses of cancer patients, Langer et al., 2007; Manne et al., 2007). It may be that caregivers are dissatisfied with the relationship and therefore avoid engaging in discussions of emotions, for example; or it may be that their inhibition of expression creates dissatisfaction, or it may be that there is bidirectional flow! To examine these relationships longitudinally, Manne et al. (2007) assessed the protective buffering behaviours of both patients and spouses, and their distress and relationship satisfaction at three time points over an 18-month period following diagnosis of early-stage breast cancer. Buffering on the part of both patients and caregivers was found to decrease over time, whereas the high levels of relationship satisfaction remained relatively stable, suggesting that they are independent; however, buffering by either the patient or the partner contributed to patient distress and if buffering increased, so did distress. In Hagedoorn et al.'s (2011) study referred to above, longitudinal analyses found that in spousal carers high levels of protective buffering at baseline (of them by the patient) was associated with low levels of spousal relationship satisfaction, particularly where pre-cancer supportiveness from patients to carers was reported as having been relatively high. This is possibly because the buffering was seen to thwart their ability to carry out their caregiving role. Other relationship factors may also influence caregiver outcome as we now turn our attention to.

## The relationship between caregiver and patient

Many studies have examined spousal caregivers, where the relationship is characterised by being full-time, interdependent and intimate (cf. Coyne and Fiske, 1992) and thus uniquely supportive. Other studies have shown less control over the caregiver 'types' recruited to the study and have included informal caregivers with varying degrees of association – mothers, fathers, siblings, daughters, friends. Pinquart and Sörensen (2003) hypothesised that differences in psychological and physical health would be greater among spousal caregivers than non-spousal caregivers, for female rather than male caregivers, and for older rather than younger caregivers. While a study of caring for an older adult only, their results did support these hypotheses, and throughout this chapter we have highlighted gender or age where they have moderated findings. Poulin and colleagues (2010) found that active helping of a spouse predicted greater positive affect in caregivers when illness status, functional impairment and 'being on call' was controlled for, but particularly where there was a perceived interdependence with their spouse, i.e. where the caregivers agreed with statements such as 'I need my spouse as much as h/she needs me'. Helping and being on call generally predicted negative affect where interdependence was low. Such findings show that interdependence may 'buffer' any negative effects of helping behaviours in patient–carer dyads but also highlight that not all aspects of the caring role are negative. What is becoming increasingly clear is that, as well as the nature of the caregiver–patient relationship, the quality of the relationship between these individuals influences the outcomes of caring for both parties. Furthermore, coping together, described as 'dyadic coping', where both members of a partnership are engaged in coping with the stressor, even where it is only one that is directly affected, for example, with a cancer diagnosis (Hagedoorn et al., 2008; Badr et al., 2010) has been found to increase adjustment outcomes including maintained relationship functioning (see review, Traa et al., 2015).

### Relationship quality

De Vellis et al. (2003) stress that understanding the nature and processes in dyadic relationships is beneficial to our understanding of adjustment to illness. Social support research has not consistently explored the relationship between those studied in terms of the nature and quality of the interaction, and yet the reciprocal and interdependent relationships that people engage in are crucial. This reciprocity is represented in Figure 15.3, where the relationship depicted is that of a marriage. It has been observed that illness can cause a 'stress spill-over' effect by adding to existing marital challenges and introducing further opportunities for conflict and strain. In a daily diary study with 50 healthy couples in a long-term marriage, greater marital satisfaction was associated with both the expression and receipt of gratitude (Gordon et al., 2011), suggesting that even in long-standing relationships relatively simple gestures of thanks can be beneficial. In the context of caring for someone with illness or disability, feeling 'unappreciated' can be a frequent source of stress or burden (see later section). Working at maintaining a good relationship quality, or preventing it from becoming any worse (if it was not particularly good to begin with!) is extremely important if illness adjustment is to be optimal for both partners, and this may be particularly important where the threat to life is significant, for example in lung cancer (Badr and Taylor, 2008).

Banthia et al. (2003) reported that the quality of a relationship can moderate the effects of individual coping, finding that prostate cancer patients in strong relationships experienced less distress than those in less strong relationships, even when they engaged in mal-adaptive coping strategies such as avoidant coping and intrusive thinking. Williamson et al. (1998) distinquish between

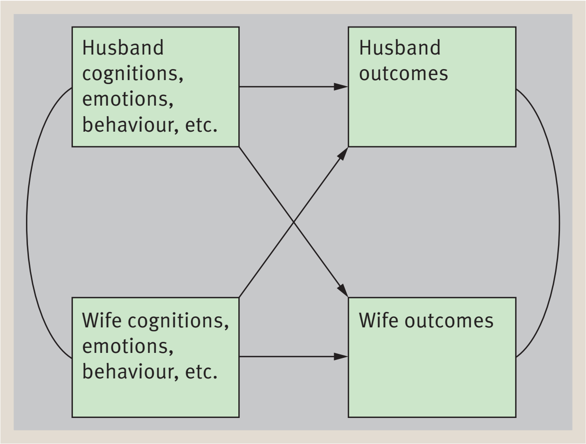


**Figure 15.3** The interdependence model of couple adjustment

*Source*: DeVellis, Lewis and Sterba (2003: 263).

depressed caregivers and resentful caregivers in their cross-sectional study of 75 cancer caregivers: depressed caregivers reported close, communal and intimate relationships with the patient, and this closeness created the restrictions on their own activities (i.e. they wanted to be with the person they cared for), whereas resentful caregivers reported less close relationships and reported their activity restriction to be predicted by severity of patient symptoms (they were restricted out of the necessity to provide care). This important, but subtle, distinction between depressed and resentful caregivers may help to explain differences in longer-term caregiver outcomes. Thompson et al. (2002) also found that resentful caregivers tend to provide overly controlling and overprotective care, and they suggest that such caring styles may undermine patient autonomy and progress. More research that explores the causes of caregiver resentment is required as it may offer potential opportunites for intervention, to the benefit of both parties.

Relationship quality is also likely to interact with motivations to commence and to continue to provide care (see Lyonette and Yardley, 2003). Badr and Taylor (2008) report how relationship maintenance behaviours, including strategies of positivity, providing assurance, using social networks, and sharing tasks, were greater in those who were less distressed (whether spousal carer or person with lung cancer) and that, over time, such behaviours, when carried out by both individuals, were beneficial to dyadic adjustment. Traa and colleagues (2015) echo this in their systematic review of 33 studies of dyadic coping in cancer, where open and constructive communications between the couple, supportive behaviours (in both), positive dyadic coping (for example, through joint information-seeking or sharing of feelings) and joint problem-solving, were related to better relationship functioning.

### Couple identity

Another aspect that may mediate the stress of caregiving for a spouse is that of 'couple identity', whereby the relationship takes on its own identity, rather than being seen as two separate individuals. In a relatively new field of enquiry, Badr and colleagues (Badr et al., 2007) found that the extent to which a healthy spouse saw their relationship with their ill spouse as part of their self-concept (reflecting the importance to them of being part of a couple) partially mediated the effects of perceived overload, relational changes, and loss of independence and loss of 'self' on mental health scores. Although cross-sectional, and involving relatively established caregivers (average of over five years), it is likely that this study will stimulate more research into this construct.

It is becoming clear from the research reviewed above that any stress experienced by a caregiver does not stem solely nor directly from what the caregivers *do* but rather from the meaning they ascribe to what they do (Dobbins, 2007).

### WHAT DO YOU THINK?

If you are in a relationship, what does it mean to you? Do your close personal relationships offer an implicit extension to how you see yourself? While research seems to suggest that couple identity is a positive factor when examining the mental health of members of the couple, can you think of any situations where there are possible risks to having a strong 'couple identity', perhaps at the expense of a strong sense of self? What about when the couple separates or one of the couple is widowed? What implications may there be then for wellbeing?

## Dyadic perceptions, shared and discrepant beliefs

Given the individual nature of health and illness beliefs, stress appraisal and coping responses, it cannot be assumed that family caregivers and those they care for will exhibit similar beliefs and responses. A growing avenue of research is exploring whether differences in the beliefs and responses of informal caregivers and their partners, or other relatives, influence illness outcomes (e.g. Morrison, 2001; Figueiras and Weinman, 2003; Sterba et al., 2008; Vilchinsky et al., 2011; Band et al., 2015).

Individuals in caring dyads may hold different and diverging beliefs about the illness itself: for example, the illness representations (see Chapter 9 ☛) of identity, timeline, causes, consequences and control/cure may differ between patients, caregiver spouses and significant others. Weinman et al. (2000) found that, following a heart attack, participation in rehabilitation exercises could be predicted more from spousal beliefs, particularly where the spouse attributed the heart attack to the patient's poor health habits (internal cause) than by the patient's own attributions. Figueiras and Weinman (2003) further examined the illness representations of 70 patient–partner dyads following a heart attack and distinguished between couples who shared 'similar positive' perceptions, 'similar negative' perceptions or 'conflicting' perceptions. The most negative perceptions and conflicting perceptions emerged in relation to perceptions of control/cure, with shared positive perceptions more evident in relation to the identity, timeline and consequences dimensions. Dyads with shared positive perceptions fared better in terms of lower disability, fewer sexual functioning difficulties, less health-related distress, greater vitality and better global adjustment than dyads with negative or conflicting perceptions.

As one might expect, caregivers provide support to an ill partner, parent, child or friend primarily because they think it is needed; however, as discussed above, this does not mean that care recipients will perceive the care and social support received as positive or helpful. This discrepancy is important: e.g. differences in perceived care needs between the caregiver and the care recipient may exist. A study by Dagan and colleagues (Dagan et al., 2011) highlights how personal control beliefs can influence individuals' responsiveness to spousal behaviour perceived as either supportive or unsupportive. They hypothesised that people with relatively low personal control beliefs would be more reactive to both positively and negatively perceived support from their partner than people relatively high in personal control, because those high in perceived control 'need' the support less as they are better able to cope independently. In support of this hypothesis is research regarding the benefits of internal control beliefs (see elsewhere in this chapter and Chapter 12 ☛), and also people relatively low in control have been found to make more use of coping strategies such as social reliance (Elfström and Kreuter, 2006). Additionally, those low in support may be more distressed by receiving supportive behaviours that they perceive as unhelpful, i.e. mismatched to their needs. Dagan's sample of 70 patients newly diagnosed with colorectal cancer and their partners (52 male patients, 18 female patients, thus 52 female partners and 18 male partners) were assessed at three months (baseline) and nine months (follow-up) following diagnosis, in terms of their perceived spousal supportive (SSL) behaviour (e.g. Can you talk with your partner openly and share your feelings with him/her?) and unsupportive (SSL-N) behaviour (How often does your partner . . . make disapproving remarks towards you?). Participants also completed a measure of their sense of personal control (Pearlin and Schooler's seven-item Mastery list) and their depressive symptoms (Center for Epidemiologic Studies Depression Scale CES-D).

Higher personal control was moderately associated with lower levels of distress for both patients and partners, however the hypothesised associations between patients' perceived supportive and unsupportive spousal behaviour and distress were not however significant. In contrast, for carers, their own distress was moderately associated with their perceptions of the supportive and unsupportive behaviour received from their spouse patient. In spite of the different association, patients' and partners' perceptions of supportive and unsupportive spousal behaviour were moderately positively associated, reflecting congruence at least in the nature of support considered supportive or not supportive. Also for both patients and partners, the interaction between perceived spousal supportive behaviour and personal control at baseline predicted follow-up distress. Those who perceived more spousal support reported less distress over time, *but only if they were relatively low in personal control* and correspondingly, partners (but not patients) who perceived more unsupportive spousal behaviour reported more distress, again only if they were relatively low in personal control. Why spousal partners low in control are more affected by unsupportive behaviour than are patients who are low in control and who perceive their carers as being unsupportive is unclear; however, it may be, the authors suggest, that for caregiving partners relatively low in control, perceiving unsupportive behaviour from the patients is interpreted as a sign that they are failing as caregivers, which may create increased distress for them in that role.

Such findings support the idea that those high in personal control beliefs possess coping skills required for their adaptation and are less reliant on others (although coping responses were not assessed and therefore this assumption is not testable in this study). However, the data do suggest that interventions to reduce distress should probably prioritise those people who are relatively low in personal control. Such findings also contribute to our understanding of who benefits from social support by showing that the effects of perceived spousal supportive and unsupportive behaviour on distress are qualified by personal control. By taking a dyadic approach, we can see in these data that patients and partners may perhaps respond differently to unsupportive spousal behaviours, even when gender is controlled for, and, if replicated, such a finding has important implications for when developing interventions or services.

This dyadic approach to coping with illness and caregiving research is growing. As described in Chapter 11 ☛, stress-coping theories have tended to focus on the individual; however, increasingly a more systems-led approach is being taken, in particular exploring patient–carer dyads within, typically, couples. A key proponent of this approach is Guy Bodenman who describes a systemic–transactional model (STM) of stress which develops the transactional model of stress-coping of Richard Lazarus (e.g. Lazarus and Folkman, 1984) which was discussed fully in Chapter 11 ☛. The STM considers the interdependent relation between both members of a dyad and the reciprocal influence each has on the beliefs and outcomes of the other, and, crucially, acknowledges and enables measurement of the fact that the couples relationship can be both affected by, and a source of, stress (Bodenmann, 1997; Falconier et al., 2015). This intra-dyadic stress, or relationship stress (Bodenmann et al., 2007) can further influence the effects of extra-dyadic stress, such as illness in one of the dyad. How members of the dyad cope, either separately or together, will also interact to influence outcome, such as was shown in a study of couples coping with metastatic breast cancer where shared positive coping benefited the adjustment of both, whereas shared negative coping was associated with greater distress, particularly among patient care recipients (Badr et al., 2010). In another study of long-term family caregivers (not all co resident and with wide variation in impairment of the care recipients), discrepancies between a caregiver and their care recipient in terms of appraisals of the caregiving role, specifically in terms of the difficulties encountered (caregivers reported more than care recipients), was predictive of caregiver, but not care recipient, perceived relationship strain (Lyons et al., 2002). It appears that discrepancy may differentially affect caregivers and care recipients, with further differences seen according to the outcome examined.

The importance of discrepancy exists in parent–child dyads as well as within spouse caregiver–recipient dyads. As reviewed in Chapter 14 ☛ parent–child dyads may converge and diverge in terms of their beliefs about an illness and its symptoms, depending on various factors, including the child's current health status. Parental over- or underestimation of a child's problem areas can have implications for parental caring behaviour. Furthermore, patient, partner or parent ratings also often diverge from health professionals' ratings of patient's QoL, activity or mood levels. This could lead to misunderstandings about treatment options or their usefulness, which may, as Janse et al. (2004) note, have implications for non-adherence. It may be that assessing both the 'patient' and a significant other will in fact give a more complete picture.

Longitudinal evidence is obviously needed which can explore causal relationships more fully. For example, using the IPQ-R (see Chapter 9 ☛) Sterba and colleagues (Sterba et al., 2008) found that, unlike in some of the conditions described above, couples shared similar beliefs about rheumatoid arthritis. Specifically where there was congruence concerning women's personal control over the illness and its cyclic nature, there was better psychological adjustment in women assessed four months later, even when controlling for their initial psychological adjustment, arthritis disability, education, years married, and global marriage rating. Similarly, although beliefs about chronic fatigue syndrome were found to be relatively congruent in a review of significant others and patients, other beliefs in their own right predicted both caregiver responses and patient outcomes (see review of Band et al. 2015). In their own empirical study, the same authors (Band et al., 2014) found that, where significant others were high on Expressed Emotion (both critical comments and emotional over involvement (EOI) parameters), the fatigue severity and depressive symptoms of the patient were worse when followed up after six months. Furthermore, EOI also predicted fatigue severity, and EOI was higher in parents than in partners. This supports earlier cross-sectional findings whereby playing down or minimising CFS and its consequences on the part of the spouses was associated with poorer patient outcomes (Heijmans et al., 1999). In this study, perhaps surprisingly, spouses being pessimistic about the illness timeline (i.e. thinking the illness was more chronic than patients thought it was) was associated with better patient outcomes.

In addressing perceptions of psychosocial adjustment to illness, it should not be surprising to find that any discrepancies in beliefs within a dyad are subject to fluctuations. This has been demonstrated, for example, in a study of 81 couples where the male had received a diagnosis of prostate cancer (Ezer et al., 2011). Exploring firstly whether belief incongruence existed, they found significant congruence in most domains of psychosocial adjustment (vocational, domestic, environmental, family relationships); however, incongruence in perceptions of healthcare received (wives more distressed by healthcare), psychological distress (husbands higher) and social activities (husbands more distressed about social relationships) existed at the time of diagnosis. Examining next whether (in)congruence changed over the first 12 months following diagnosis; at three months, wives continued to be more distressed by healthcare expectations and men remained more psychologically distressed; however, men now also showed significantly discrepant and higher distress regarding sexual relationships. Men's higher psychological distress and greater distress regarding sexual relationships persisted to the 12-month follow-up. This is consistent with other studies of prostate cancer, where challenges to sexual function have been shown to impact on a masculine identity, and it appears that spouses may be more able to accept changes in this life domain than the men themselves (Resendes and McCorkle, 2006).

In concluding this section, it appears that as well as relationship type and quality playing a role in the caregiver (and care recipient) experience, the beliefs within a dyad concerning the illness and with the giving and receiving of support, and the coping strategies which are used within a dyad, all have a contribution to make. While it appears that shared perceptions and dyadic coping are more adaptive than discrepant and individual responses, there remains a need for further study, both within adult and parent–child dyads.

## SUMMARY

This chapter has described the impact that illness in a significant other can have on individuals within a family, many of whom will find that they become primary caregivers. We have described what is meant by an informal caregiver as well as considering whether the label 'carer' is helpful to those involved or not, and we have presented evidence of a complex range of influences on the caregiving role and its possible outcomes. This complexity of influence places many challenges in front of a researcher or practitioner wishing to assess caregiver outcomes, and this is against a backdrop of an increased societal need for informal care, and improvements in carer-relevant policy and services. Relationship factors have to be considered as well as individual, social and cultural influences on caring uptake and the response to the caregiving role.

Importantly, we have highlighted that caring, as being ill, does not bring with it inevitable negative consequences. We have also addressed a new and important area of research that highlights that perceptions of illness and its consequences can vary in couples living with illness, and how such discrepancies and the interdependence in relationships can influence a range of outcomes. Acknowledging and identifying the consequences of caring enables interventions to be implemented for the benefit of caregivers and those they care for, as well as potentially for society in terms of reduced social and healthcare costs of caring for caregivers who themselves experience significant stress, burden or ill health.

## Further reading

Pickard, L. (2015). A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032. *Ageing and Society*, 35, pp 96–123 doi:10.1017/S0144686X13000512

This paper described how the projections of need for informal care will soon outstrip the available supply of informal, primarily family caregivers. Given this there is a need to develop other sources of care, including perhaps innovative policy and technology solutions.

Cipolletta, S., Morrison, V. and Vilchinsky, N. (2020). Caregiving and social support in the context of chronic illness, *Editorial, Frontiers in Psychology*, doi: 10.3389/fpsyg.2020.620357

This editorial introduces a collection of 26 articles addressing a diversity of topics in caregiving, from cultural and relational role expectations to caregiving in specific contexts and developing e-health interventions. Worth a browse

## Key papers

Adelman, R.D., Tmanova, L.L., Delgado, D. et al. (2015). Caregiver burden: a clinical review. *JAMA*, 311: 1052–1059. doi:10.1001/jama.2014.304

A well-informed review of evidence with clearly tabulated checklists for discussing and assessing caregiving responsibilities and caregiver needs. The crucial role of physicians in recognising and supporting caregivers in order to optimise caregiver health and that of the care recipient is highlighted alongside a summary of existing caregiver interventions.

Roth, D.L., Fredman, L. and Haley, W.E. (2015). Informal caregiving and its impact on health: a reappraisal from population-based studies, *The Gerontologist*, doi: 10.1093/geront/gnu177

A potentially important paper in that it questions the evidence as to negative impacts of caregiving and in doing so highlights the positive aspects, such as mortality and longevity gains.

## Weblink

www.carersuk.org

Carers UK is a charity led by carers, for carers, but useful information for researchers can be downloaded from surveys and reports commissioned by the charity.

# Chapter 16

# Pain

## Learning outcomes

By the end of this chapter, you should have an understanding of:

- different types of pain
- the prevalence of chronic pain
- psychological factors that influence the experience of pain
- the gate theory of pain
- the neuromatrix theory of pain
- behavioural and cognitive-behavioural treatments of acute and chronic pain

## No pain, no gain

Look at pictures of athletes at critical moments in competition, and their face may be a rictus of pain. Professional cyclists wear sunglasses for much of the time, partly to keep the sun and flies out of their eyes, partly to hide their suffering so they will not show weakness to their competitors. The ability to 'suffer' is seen as central to their sport. So central is this experience to cycling, one of the best-known commercial training programmes is known as 'The Sufferfest', and cyclists report training in their 'pain cave'. Eddy Merckx, the one true great of cycling has even been cited as saying: 'Cyclists live with pain. If you can't handle it, you will win nothing. The race is won by the rider who can suffer the most.' So, why do, at least some, cyclists welcome even seek pain, while most of us fear and avoid it. The secret may be in the *meaning* of pain. Pain in cycling indicates power, victory over self and others. It is a positive experience. By contrast, pain associated with disease is likely to evoke fear, apprehension, as well as feelings of lack of control and concern about the disease status. It is not welcome. Central to the experience of pain is our interpretation of its causes, nature, and consequences. Depending on the interpretation we accord to it, our experience of pain, including its perceived magnitude, may vary considerably. Pain is a psychological as well as physical experience.

## Chapter outline

**Pain occurs in a variety of medical conditions, and sometimes in the absence of any physical problems. So prevalent is this experience that we have taken an entire chapter to examine its aetiology and treatment. This chapter examines a number of physiological and psychological explanations for our differing experiences of pain. It first examines the experience of pain: how various types of pain are defined, how prevalent they are, and how we respond to acute and chronic pain. It then considers the role of emotion, cognitions and attention in mediating the experience of pain. The next section describes the gate theory of pain developed by Melzack and Wall, which explains how both biological and psychological factors combine to create our experience of pain. Finally, the chapter goes on to consider a number of psychological interventions used in the treatment of both acute and chronic pain. Additional or alternative treatments for many of these conditions are considered in Chapter 17 ☛, which may usefully be read in conjunction with this chapter if you are reading about the totality of psychological treatments that patients may encounter.**

# The experience of pain

Pain is a familiar sensation for most of us. It is functional. It is unpleasant, and it warns us of potential damage to the body. A reflex action when we feel pain is to pull away from its cause or to try and reduce it in some way. Pain may also signal the onset of disease and is the symptom most likely to lead an individual to seeking medical help. Although the experience of pain may seem almost self-explanatory and constant, the International Association for the Study of Pain (see www.iasp-pain.org) has relatively recently revised its definition of pain to:

> An aversive sensory and emotional experience typically caused by, or resembling that caused by, actual or potential tissue injury.

This definition is designed to encompass some of the key facets of pain and our response to it, which they indicate to be:

- Pain is always a subjective experience that is influenced to varying degrees by biological, psychological, and social factors.
- Pain and nociception are different phenomena: the experience of pain cannot be reduced to activity in sensory pathways.
- Through their life experiences, individuals learn the concept of pain and its applications.
- A person's report of an experience as pain should be accepted as such and respected.
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological wellbeing.
- Verbal description is only one of several behaviours to express pain; inability to communicate does not negate the possibility that a human or a non-human animal experiences pain.

The absence of pain is problematic. People with a condition known as congenital universal insensitivity to pain usually die at a young age because they fail to respond to illnesses of which the main symptom is pain (such as appendicitis) and to avoid situations that risk their health (Nagasako et al., 2003). They could, for example, receive extensive burns by sitting too close to a hot fire without experiencing the warning signs that most of us take for granted. Nevertheless, despite these survival benefits, when pain lasts a long time, it feels destructive and problematic. It can be so difficult to ignore that it takes over our lives. It may endure long after the time of any physical damage, or even be experienced in areas of the body that no longer exist. Many people who have had an arm or leg amputated go on to experience **phantom limb pain**, in which they feel pain in their non-existent limb, sometimes for many years. Accordingly, pain can also be maladaptive and contribute to long-term problems for an affected individual.

## Types of pain

Clinical definitions have categorised various types of pain, including:

- *Acute pain*: despite most people's concept of acute pain as lasting only a few minutes, acute pain is defined as pain lasting less than three to six months (Turk and Okifuji, 2001). Some episodes of acute pain, usually involving some form of injury, may occur only once, and generally the pain disappears once the damaged tissue has healed. However, acute pain may be recurrent. Conditions such as **migraine**, headaches or **trigeminal neuralgia** may involve repeated episodes of pain, each of which can be defined as 'acute' but which are also part of a longer-term condition.
- *Chronic pain* is pain that persists past normal healing time and hence lacks the acute warning function of physiological nociception. Usually, pain is regarded as chronic when it lasts or recurs for more than three to six months. Chronic pain generally begins with an episode of acute pain that fails to improve over time. In this category, there are two broad types of pain: (i) pain with an identifiable cause such as rheumatoid arthritis or a back injury, and (ii) pain with no identifiable cause. The latter is not unusual: 90 per cent of cases of back pain are generally considered to have no known physical cause (Koes and Tulder, 2006). Chronic pain can, itself, be divided into two types:
    1. *Chronic benign pain*: in which long-term pain is experienced to a similar degree over time. An example of this may be lower back pain.
    2. *Chronic progressive pain*: here, the pain becomes progressively worse over time due to the progression of a disease such as rheumatoid arthritis.

Another way of thinking about types of pain is to think about the nature of the pain. Here, three dimensions of experience are frequently used:

- *the type of pain*: including stabbing, shooting, throbbing, aching, piercing, sharp and hot;
- *the severity of pain*: from mild discomfort to excruciating;
- *the pattern of pain*: including brief, continuous and intermittent.

phantom limb pain

a phenomenon that occurs following amputation of a limb, in which the individual feels like they still have their limb, and the limb is in pain

migraine

a headache with symptoms including nausea, vomiting or sensitivity to light; associated with changes in vascular flow within the brain

trigeminal neuralgia

a painful inflammation of the trigeminal nerve that causes sharp and severe facial pain

## The prevalence of pain

It would be difficult to find many people who had not experienced some degree of acute pain in the last month or so, but chronic pain is also remarkably common. Fayaz et al.'s (2016) meta-analysis of 19 studies exploring this issue in the UK, found that between 35 to 51 per cent of the general population reported experiencing some degree of chronic pain, and between 10–14 per cent had sufficient pain to be moderately to severely disabling. As may be expected, rates were higher among older adults, with around two thirds of people over the age of 75 experiencing these problems. More surprising, perhaps, were findings that up to 30 per cent of people aged between 18 and 39 years also experienced this problem. In the US, Dahlhamer et al. (2018) found a 20 per cent prevalence rate of people reporting chronic pain, while 8 per cent had 'high impact' chronic pain which severely impacted on their work, social, recreational, or self-care activities.

Women are more likely to report pain than men across all age groups, as are those who are divorced or separated. People with jobs that involve 'high physical strain' are also likely to report chronic pain than those in more sedentary jobs. Another way of looking at the prevalence of pain is to examine the use of analgesics within the general population. A Finnish study gives us some relevant data. Turunen et al. (2005) found that in a population sample of people aged 15–74 years old, 8.5 per cent used over-the-counter analgesics daily, and 13.6 per cent used analgesics at least several times a week. In the USA, the percentage of people using strong opioids for the management of pain increased from 11.5 per cent of the population to 24 per cent between 2001/2 and 2013/4 (Nahin et al., 2019).

According to Blyth et al., (2003), the most frequently reported causes of pain among adults, are injury (38 per cent), sports injury (13 per cent) and a 'health problem' (29 per cent). Nearly 80 per cent of those who reported having chronic pain had consulted a doctor about it in the six months before the survey. An interesting study of Danish schoolchildren aged between 12 and 19 years (Rathleff et al., 2013) found a specific cause of back pain among them. Twenty per cent reported experiencing almost daily pain. More than half reported pain or discomfort in their lower back; a quarter experienced a decreased function as a consequence of this pain. The pain appears to have been caused mainly by carrying a heavy satchel over one shoulder; a finding that instigated the government recommendation of the use of rucksacks to even the load onto both shoulders.

Pain is a primary reason for visiting a doctor. Mantyselka et al. (2001), for example, reported that 40 per cent of primary care visits were the result of pain; 21 per cent of their sample who attended their doctor with a primary symptom of pain had experienced it for more than six months, and 80 per cent reported limited physical function due to their pain. The most common areas of pain were in the lower back, abdomen, and head. Among particular patient groups, levels of pain can be even higher. Potter et al. (2003), for example, reported that 64 per cent of people receiving care from a hospice, the majority of whom had a diagnosis of terminal cancer, reported pain as one of their primary symptoms.

## Living with pain

To say that chronic pain is unpleasant is understating its potential effects. Pain can have a profound effect on an affected individual and those close to them; so much so that many people with chronic pain organise their day around their pain. They may be prevented from engaging in physical, social, and even work activities. Some may even find looking after themselves on a day-to-day basis difficult. It may affect social and marital relationships, resulting in conflict between couples, which may itself exacerbate the pain (Leonard, Cano and Johansen, 2006). It may also affect an individual's financial situation, as they may lose their job because of pain-related disability. It is noteworthy that people who have physically demanding jobs are more likely to experience pain than those in sedentary jobs, and most likely to lose them as a consequence of any physical limitations caused by pain (Eriksen et al., 2003). Osborn and Rodham (2010) identified a number of psychological reactions to the presence of pain, including confusion and worry, a feeling of 'assault on the self' and changes in self-identity, and social challenges. Clearly, there are more negative consequences than simply the experience of chronic pain. In a further synthesis of qualitative studies, Crowe et al. (2017) identified five 'meta-themes' common across most studies of chronic pain: (i) 'the body as obstacle', representing the body as incapacitating and no longer functional, (ii) 'invisible but real', involving a sense of not being believed and stoically keeping things to oneself, (iii) 'disrupted sense of self', involving changes in the experience of 'what is normal' and changed relationships with self, others, and the environment, (iv) unpredictability, and (v) 'keeping going' including a balancing act between hope and resignation, dependency and withdrawal, and feeling suicidal and fighting.

Not surprisingly, levels of depression and anxiety are high among people with chronic pain (Hampton et al., 2019). However, the direction of association between depression and pain is not always clear. Some people who are depressed or anxious may focus on bodily symptoms or minor aches and pains and be more likely to perceive them as painful 'symptoms' of disease than people who are not depressed. That is, mood disturbance may lead to high levels of reporting of pain symptoms. In other cases, the strain of living with pain and the restrictions on life it imposes may lead to low mood and/or anxiety. There may indeed be a reciprocal relationship between depression and pain. People who are depressed or anxious may feel unable to cope with their pain and thus limit their activity to minimise any pain they experience. This lack of activity may lead to a stiffening of joints and muscles, which results in increased pain when they do attempt activities. This, in turn, may restrict their activity further and increase their depression. And so, the cycle continues. The case of Mrs F provides an example of this.

## Case history: Mrs F

I have a headache all the time. Some days are worse than others. When it's bad, its pounding and I cannot escape it. When I have a good day, I can feel it, but it is not so dominating. When I have a bad day, I don't want to do anything. I struggle to go to work as I do not want to lose my job. But I take 10 hours to do 5 hours' work. I can't concentrate, everything feels bad. I just want to lie down and not move. I don't want to do things at the weekend, but I know I must. But it really gets me down. I do things, but I'm not really all there . . . I don't enjoy them really. So, even when I do things I should enjoy I don't enjoy them like I used to . . . and knowing this makes me feel depressed, as I cannot see an end to the pain . . .

An additional factor that may influence how people respond to pain comes from their interactions with their social environment. Pain brings a number of costs, but it may also bring a number of (often unconscious) benefits to both the person in pain and those around them. Bokan et al. (1981) identified three kinds of 'gain' or reward associated with pain:

1. *primary (intrapersonal) gain*: occurs when expressions of pain (wincing, clutching painful areas, and so on) result in the cessation or reduction of an aversive consequence – for example, someone taking over a household chore that causes pain;
2. *secondary (interpersonal) gain*: occurs when pain behaviour results in a positive outcome, such as expressions of sympathy or care;
3. *tertiary gain*: the pleasure associated with helping an individual with pain

A further type of gain may stem from an individual's beliefs about their pain. If they believe that when they do certain things, the pain they experience indicates they are causing themselves physical harm, the relief gained from avoiding that activity may also reinforce inaction and lack of activity.

**IN THE SPOTLIGHT**

## Ethnicity and pain

An anaesthetist who had worked in a variety of countries was describing the amount of anaesthetic he had to give to people having the same operation in different countries across Europe and the USA. He suggested that if the UK acted as a sort of 'baseline' against which to compare other countries, then people in the USA liked to be knocked out completely and not to experience any pain at all – so they needed more anaesthetic than people in the UK. By contrast, he suggested that people from Scandinavian countries expected to experience a reasonable amount of pain following surgery, so they needed less anaesthetic than people from the UK. Whether his story is true or not, it raises issues about whether there are differences in pain expectations and tolerance across countries and cultures.

A number of studies have examined similar issues, studying ethnic differences in the experience of both acute and chronic pain in the USA. In a review of their findings, Perry et al. (2019) concluded that there is consistent evidence of significantly higher preoperative and postoperative pain intensity scores reported between African American and Hispanic individuals compared with non-Hispanic Whites.

These data evoke a number of questions. The first question that has to be asked is why are we interested in this type of issue? Why should we expect such differences, and what if anything do they tell us? Are any differences biological or genetic? Are they the result of sociocultural factors? Are they cognitively mediated? Are they the results of biased reporting of results – are there studies out there that have found no differences

*(continued)*

in pain experiences and responses between different social and ethnic groups that do not get reported? The data tell us very little about the origins of any between-group differences – and lead to dangers of ethnic stereotyping.

Ironically, these emerging stereotypes also conflict with at least some health professionals' beliefs about ethnic differences in pain thresholds. What evidence there is suggests that African Americans are likely to be offered less analgesic than their White counterparts, at least in some US hospitals (see Chapter 2 ☛). But stereotypes do seem to influence our expectations of different social groups and how they are treated. Morris (1999), for example, noted that the least powerful groups within any culture are the most likely to experience disregard for their pain – and the most powerful are likely to have access to good pain relief should it be required. He cited historical examples of the disregard of pain among insane people in the eighteenth century, and Black American women in the nineteenth century. One interesting belief noted by Morris, was that in the eighteenth and nineteenth century labourers were thought to have 'coarse' nerves that freed them from pain while undertaking hard manual work, while upper-class men and women were thought to have 'refined' nervous systems that would not allow them to engage in such labour without harm. Care should be taken not to establish more racial or ethnic stereotypes.

*Source*: Perr, Baumbauer, Young et al. (2019).

These various reward systems can lead to considerable problems and make people within them difficult to treat (Steinmetz and Tabenkin, 2001). If a person's expressions of pain are rewarded by outcomes they desire, and those around them gain satisfaction from providing them, this may result in them doing less and less to help themselves (see the 'Case history', Mr J). This in turn may lead to increasing inactivity, muscle stiffness and wastage, which may exacerbate any problems they may have. Brena and Chapman (1983) described the so-called 'five Ds' that may result from such an environment:

1. dramatisation of complaints;
2. disuse through inactivity;
3. drug misuse as a result of over-medication in response to pain behaviour;
4. dependency on others due to learned helplessness and impaired use of personal coping skills;
5. disability due to inactivity.

By contrast, many people cope well with chronic pain for significant periods of time without encountering such problems, and many environments will encourage activity and minimise the pain experience. People with arthritis, for example, who are well supported may be encouraged by their partners and friends to take part in activities which maintain function and prevent joint stiffening and other factors that contribute to pain. The

## Case history: Mr J

Mr J had experienced chronic backache for a number of months. Over this time, he found that certain activities increased his pain. Activities such as standing while raising his hands and lifting proved particularly difficult. Unfortunately, these activities corresponded to those involved in his usual task of preparing the evening meal. He worried that any pain he experienced was because of the position he was adopting while doing the cooking. As a result, although he did not complain about doing the cooking, he showed his pain through winces and an awkward stance at the worktop. His wife, alert to his non-verbal behaviour and not wishing her husband to be in pain, offered to do the cooking for him on a couple of occasions, and soon he stopped doing it altogether. As a result, Mr J felt better because he was avoiding his worries and a boring task, and Mrs J felt better because she cared about her husband and wanted to do the best she could for him. It seems like a win–win situation. However, both parties may eventually lose as a result of this process: Mr J because his increasing inactivity will lead to further back problems; Mrs J because she will potentially become overburdened and resentful of her role as a 'carer'.

emotional support that such people provide may even influence their experience of pain. Che et al. (2018), for example, identified social support as providing benefit through decreasing the adverse influence of pain-related distress, reappraising pain related distress and facilitating coping attempts. Interestingly, patients with pain report similar levels of satisfaction with their partners whether they are inappropriately 'supportive' or encourage independence and more positive coping strategies (Holtzman et al., 2004).

## Socio-communication and pain

Reflecting the previous discussion, expressions of pain fit within a wider model of what has been termed 'socio-communication in pain' (Hadjistavropoulos et al., 2011). This is premised on the basis that pain behaviours are a form of communication, the expression of which is functional. That is, they are designed to elicit a response from other people who receive them. This argument may be quite radical. Finlay and Syal (2014), for example, adopted an evolutionary perspective to argue that women may find giving birth so painful because over millennia women who expressed high levels of pain during labour were more likely to gain support while doing so, which may have increased both their and their child's survival chances, resulting in evolutionary pressure favouring such behaviours. By contrast, ecstatic religious experiences involving the intentional self-infliction of pain including self-flagellation, body piercing, and being carried on wooden frames held up by metal hooks can occur in the absence of any experience of pain and have other intended messages of shared exultation and joy. Another context in which pain communication is almost critically important is in the context of medical or surgical care. Here, fear of not receiving sufficient pain medication may exaggerate expressions of pain, while confidence in a clinician may both reduce the pain experience and the expression of pain. The reporting of pain in each of these differing contexts may reflect 'actual' pain experiences as they have been shown not only to influence reporting of pain; they have also been shown to influence activity in brain areas known to modulate the pain experience (Jackson, Meltzoff and Decety, 2005).

The expression of pain can be deliberate or incidental. Verbal reporting of pain usually involves self-awareness and attention being given to the pain experience. It also allows construction of a desired response; whether this is to be honest in representing pain, or to dissemble to gain sympathy, social desirability and so on. Non-verbal responses are more likely to be unintentional (but may also carry deliberate messages). A common way of communicating pain is through our facial expression; by, for example, lowering of brows, narrowing of the eyes, raising the upper lip, or parting the lips. These may be faked, and faked quite effectively. Both healthcare professionals and lay people find it difficult to discriminate between faked and 'real' pain signals (Steinkopf, 2016). We generally understand the language of pain, and the ability to both express and understand pain is a process refined over time as it is of clear evolutionary benefit (Ickes & Decety, 2009). It may also be influenced by external factors such as the expressions of emotionally close individuals undergoing the same painful stimuli. Here, the facial expressions of both those involved are likely to mirror those of the other person (Gagnon, Hadjistavropoulos and MacNab, 2017). The key to understanding each pain expression therefore is to identify its function, whether to portray stoical 'manhood', gain attention or treatment from others, or show empathy with others.

## Biological models of pain

Perhaps the simplest biological theory of pain is that there are 'pain receptors' in the skin and elsewhere in the body that when activated transmit information to a centre in the brain that processes pain-related information. Once activated, this 'pain centre' produces the sensory experience of pain. This type of theory, known as a specificity theory, was first proposed in the third century BCE by Epicurus and was taken up later by Descartes and others in the seventeenth century. Von Frey (1894; see Norrsell et al., 1999) added to this theory by suggesting that our skin includes three different types of nerve, each of which responds to touch, warmth or pain. These theories were further elaborated by Goldscheider (1884; see Norrsell et al., 1999), whose pattern theory of pain suggested that pain sensations occurred only when the degree of nerve stimulation crossed a certain threshold. These basic biological models of pain, with some elaboration, remained dominant until the 1960s. They were supported by the identification of nerves that were sensitive to different types of pain, and nerve tracts that led from the skin to the spine, where they linked with other nerves before leading to the brain (see below).

These theories have one common tenet: that the sensation of pain is a direct representation of the degree of physical damage or sensation sustained by the individual. This tenet has the benefit of simplicity. Unfortunately, as we have already seen, it can easily be shown to be wrong. We have already considered a number of factors that influence our experience of pain. Three other sets of evidence have been used to challenge these simple biological theories of pain:

1. pain in the absence of pain receptors;
2. ‘pain receptors’ that do not transmit pain;
3. the influence of psychological factors on the experience of pain.

## Pain in the absence of pain receptors

Perhaps the most obvious counter to these simple biological models is evidence that many people experience pain in the absence of any nerve pain receptors. The most dramatic example of this phenomenon is known as ‘phantom limb pain’, which involves sensations, sometimes extremely painful, that feel located in a patient’s missing limb following amputation. Allami et al. (2019), for example, found that 84 per cent of Iranian war veterans who underwent a limb amputation experienced pain in the residual part of limb for significant periods of time following surgery. The prevalence of phantom limb sensations or pain experienced in the missing part of the limb were not much below this level: 77 and 74 per cent respectively. Once established, phantom limb pain frequently becomes chronic and long-lasting. Mishra et al. (2007) for example, found nearly a third of patients with a limb amputation who initially experienced phantom limb pain continued to experience significant pain despite using strong opiate medication. Interestingly, people who have their upper limb amputated are far less likely to experience phantom limb pain than those who have had a leg amputated. Unfortunately, as these data suggest, phantom limb pain is difficult to treat and can have a significant negative impact on people with the condition.

## ‘Pain receptors’ that do not transmit pain

A second physical phenomenon that presents problems for these early theories stems from the experiences of people with congenital universal insensitivity to pain, referred to above. Individuals with this condition may experience painless bone fractures and ulceration to their hands and feet, which may go unnoticed. They may also fail to identify pain as a symptom of severe disease and sustain dramatic injuries as a result of a failure to respond to danger signals. Some people with the condition may even experience ulceration of the cornea of the eye as they fail to protect against strong sunlight (Nagasako et al., 2003). Individuals with CUIP appear to have intact pain pathways, so they present the opposite problem to that posed by phantom limbs: a failure to perceive pain in the presence of an apparently intact pain pathway.

## Psychological influences on pain

A number of psychological factors have been found to influence the experience of pain. Four of the key ones are:

1. *Mood*: anxiety and depression reduce pain tolerance and increase the reporting of pain.
2. *Attention*: focusing on pain increases the experience of pain.
3. *Cognitions*: expectations of increases or reductions in pain can be self-fulfilling.
4. *Social context*: the influence of others around us.

### Mood and pain

Evidence of the influence of mood on the experience of acute pain can be found in studies in which participants are asked to rate or tolerate pain until their discomfort is too great to tolerate it any further. These have shown that people with chronic back pain who are depressed, for example, report the equivalent pain stimulus as more painful than those who are not experiencing low mood, and tolerate pain for significantly less time (e.g., Tang, et al., 2008). In a classic example of this phenomenon, Fisher and Johnston (1996) gave patients with lower back pain a simple mood induction procedure in which they were asked about either upsetting aspects of their condition or its more positive aspects. Before and after this procedure, participants were given a plastic bag into which were placed as many packets of rice as they felt able to tolerate the pain associated with the task. In comparison with their performance at baseline, participants who reported the upsetting issues (and were therefore assumed to have lower mood) performed less well. By contrast, those whose mood was improved were able to hold the same weights for a longer period than baseline. This was an important study, as it used real patients faced with a task similar to their everyday activities.

With some exceptions (e.g. Cagnacci et al., 2018), the data suggest that chronic pain has a significant negative impact on mood, and mood has a reciprocal impact on the experience of pain. Magni et al. (1994), for example, followed a cohort of over 2,000 participants with musculo-skeletal pain, and found depression both to predict future pain levels and pain to predict future depression. Changes in pain and mood are also likely to be influenced by changes in contextual factors such as life events and the context of care. Craig et al. (2017), for example, found that anxious patients experiencing pain as a consequence of spinal injury reported more pain following discharge home than their less anxious peers. Low mood can also have an indirect impact through its influence on the duration and quality of sleep (Harrison et al., 2016). The experience of depression as a consequence of long-term pain may also reduce individuals' willingness to endure pain, and lead to lower levels of engagement in potentially painful behaviours even if they are of long-term benefit (Probst et al., 2016).

## Cognition and pain

Mood may influence pain through its influence on beliefs and expectations about the nature and consequences of any pain. The types of thought that may influence the pain experience include:

- attributions concerning the cause of pain;
- beliefs about the ability to tolerate pain;
- beliefs about the ability to control pain;
- expectations of pain relief – the placebo effect.

A simple example of how attributions concerning the cause of pain may influence the pain experience was described by Cassell (1982) in a case report in which one patient's pain was easily controlled with codeine when they attributed it to **sciatica** but required strong opiate analgesia when they attributed the same pain to having cancer.

In a more experimental investigation of this process, Goli et al. (2016) subjected patients with chronic migraine to an experimental procedure in which a short film was used to influence mood (happy, neutral, sad) followed by a demanding cognitive task likely to induce some degree of headache in these vulnerable individuals. They found a direct association between mood and headache severity, with those in the happy condition experiencing least pain, and those in the sad condition experiencing the most. In addition, they found that levels of pain in the sad condition were predicted both by mood and the extent to which participants **catastrophised** about their pain. In a population experiencing more consistent pain, Dong et al. (2020) found the variance in pain reported by older adults with persistent pain was largely explained by the extent to which they engaged in catastrophising thoughts about the pain. The variance in reported pain explained by psychological factors was substantial: 16 per cent by anxiety, 17 per cent by depression, and 31 per cent by pain catastrophising. Unfortunately, when the cause of pain is particularly traumatic and the individual experiences high levels of stress or distress as a consequence, the experience of pain is likely to be magnified (Outcalt et al., 2014). Extending this response to consider the *impact* of pain, Walsh and Radcliffe (2002) found that the beliefs of people with chronic back pain who believed their pain was the result of physical damage to their spine were more reluctant to engage in exercise than those who attributed it to 'psychological' factors – because they were afraid that exercise would exacerbate their damaged back and increase their pain.

Unsurprisingly, perhaps, people who feel able to tolerate or manage their pain are less restricted by it. Maly et al. (2007), for example, found that patients with osteoarthritis of the knee (see Chapter 8 ☛) with high levels of belief in their ability to manage their pain walked

sciatica

pain down the leg, which is caused by irritation of the main nerve into the leg, the sciatic nerve. This pain tends to be caused where the nerves pass through and emerge from the lower bones of the spine (lumbar vertebrae).

(to) catastrophise

evoke an exaggerated negative attribution/expectation of a situation: 'This pain means something is seriously wrong!'

more than those with less strong beliefs. Similarly, fit cyclists who believed in their ability to control or manage their pain allowed themselves to experience more painful exercise than those with lower control beliefs (Motl et al., 2007). Individuals with high control beliefs may also *experience* less pain. Jensen et al., (2001) found that among a group of patients with chronic pain involved in a pain management programme, higher perceptions of control over pain were associated with lower levels of reported pain severity. Experimental studies also provide support. In one relevant study, van den Hout et al. (2000) randomly assigned healthy participants to conditions in which given they were given feedback indicating they had high or low levels of control over an experimental task immediately before completing a **cold pressor task** (an exquisitely painful procedure involving placing an arm in water close to freezing point – try it if you like!). Despite the initial task being unrelated to pain, it seemed to have some carry-over to the cold pressor task, which was tolerated for significantly longer by those given high control feedback than those who received low control feedback.

## Expectations of pain relief: the placebo response

One of the most fascinating phenomena associated with pain is known as the placebo response. If you were to give an inert tablet with no biochemical effects to people experiencing some degree of pain, *tell* them that it will have no effect, a percentage of those individuals (and probably quite a significant percentage) would report some relief from pain as a result of being given the 'tablet'. Red 'tablets' are more effective than blue 'tablets' in this context (Huskisson, 1974). This phenomenon is known as the placebo effect. There appears some benefit to simply being given what appears to be treatment, whether this is a tablet, injection or more culturally diverse form of treatment. Indeed, so powerful is this effect, it has been considered a clinically viable intervention (e.g. Klinger et al., 2018) with potential effects as great or greater than many biochemically active treatments.

A placebo (from the Latin, 'I please') is an inert preparation that has no pharmacological effects. Across a range of studies, the percentage of individuals to report at least a 50 per cent reduction in pain following being given a placebo ranges from a lowly 7 per cent to nearly 50 per cent across a variety of conditions and periods of time (McQuay and Moore, 2005). Its effect is not limited to pain. The placebo effect can be found to influence inflammation, the speed of wound healing, immune responses to infection, and improve symptoms from conditions as diverse as angina, asthma and depression (Humphrey, 2002). If a placebo looked like a previously prescribed active drug, the patient may not only show the degree of benefit in symptom reduction experienced during the active treatment, they may also experience the same side-effects as they had while on the active drug (Suchman and Ader, 1992).

Two key mechanisms through which the placebo effect is assumed to have its effect have been posited. The first involves a classical conditioned response to stimuli associated with pain reduction (Bąbel, 2019) and can explain findings of similar outcomes for placebos as previously prescribed active medications A more cognitive model, known as response expectancy theory, focuses on our expectations of pain or pain relief (Colloca and Miller, 2011). We *experience* a reduction in pain because we *expect* a reduction in pain. Both processes trigger a range of neurobiochemical processes related to pain mediation considered in the following sections, in the dopamine, opioid, serotonin, and endocannabinoid pathways (Colagiuri et al., 2015).

The placebo response is likely to be influenced by a range of factors including the description and administration of a treatment by a practitioner, as well as the recipient's perceptions of the practitioner's credibility, expertise, or confidence. They may also be affected by individual factors such as past experience with other medication, the desire for relief, and anxiety (Bingel, Colloca and Vase, 2011). Rossettini, Carlino and Testa (2018) provided a longer and probably definitive list of factors likely to influence the placebo response, including patient expectations and treatment history; clinician's behaviour, beliefs, verbal suggestions, positive therapeutic style, degree of patient-centred approach and social learning; the use of overt therapy and apparent dosage

cold pressor test

procedure in which participants place their arm in a mixture of water and ice with a water temperature of between 0 and 3 degrees centigrade prescribed, the modality of treatment administration (tablet, injection etc), the marketing features of treatment, and the healthcare setting. Phew! Of course, these may interfere with as well as promote the placebo response. Patients recently diagnosed as having a serious illness or patients who distrust their therapy, for example, are less likely to have a meaningful placebo response (Benedetti et al., 2007).

On a slightly tangential note, the placebo effect is considered so important and pervasive that the best trials of the effectiveness of any new intervention must involve a comparison with a placebo version of the intervention, for which trial participants have an equal expectation of effectiveness. The new intervention must fare significantly better than a placebo to be considered an effective treatment. As an example, Colloca (2019) noted that in 2011 over 4,000 clinical trials were conducted on new pain medications but produced only five new drugs, as the vast majority failed to out-perform their placebo comparison. Medical placebos are relatively easy to construct – usually a tablet or injection that looks identical to the active intervention. Psychological placebos are more difficult to construct, but typically involve as a minimum the same amount of time spent with the participants in some apparently ‘psychological’ act (e.g., a non-specific discussion of a problem) as the active therapy.

Surprisingly, perhaps, despite the frequent use of placebos by medical practitioners (Howick, 2013), there are few guidelines for their clinical use and none that appear to have been formally assigned by any medical or statutory bodies. However, an ‘expert consensus’ for their use was reported by Evers et al. (2018) which had the following headline recommendations:

1. Consider placebo effects as part of regular treatment.
2. Inform patients about placebo and nocebo effects in such a way that treatment effects are maximised, and side-effects are minimised.
3. Ensure a patient-clinician relationship that is characterised by trust, warmth and empathy in order to maximise placebo effects and minimise **nocebo effects.**
4. Train healthcare providers in patient-clinician communication to maximise placebo effects and minimise nocebo effects.
5. Prefer open-label rather than hidden placebo prescription in those cases where there is evidence for efficacy and where prescribing a placebo is legal.
6. Do not take risks (e.g., prescribing invasive treatments) to maximise placebo effects.
7. Do not consider deception a necessary component of placebo effects.

## Attention and pain

One way in which mood may influence our perception of pain is by influencing the attention we pay to any pain sensations. Depressed, and particularly, anxious people may pay particular attention to pain sensations, and this focus may significantly influence their experience of pain. Focusing on pain seems to increase its impact: focusing on other things seems to reduce it. For instance, many people who experience injuries while playing sports requiring effort and concentration do not notice the extent of any injuries until after the game has finished. Less anecdotally, there is evidence that fewer people experience pain following physical trauma at times of intense stress, such as being on the battlefield, than when similar levels of injury are sustained in less stressful situations (Beecher, 1946). This may be because of attentional factors – in the battlefield there are many important distractions from one’s own pain. However, other factors may also have been involved. It is possible, for example, that the soldiers were simply pleased to be alive following battle and thought their injury would result in them being sent away from the battlefield. The issue here, therefore, may be the meaning ascribed to the injury and pain as much as the degree of attention paid to it.

More controlled evaluations of the relationship between attention and pain have shown that the use of distraction can reduce pain, while experimental manipulations that increase attention to painful stimuli result in increased reporting of pain. James and Hardardottir (2002), for example, asked patients to take part in a cold pressor task. Those who focused on the pain were least able to tolerate it and pulled their arm out of the water significantly earlier than those in the distraction task.

nocebo effect

the opposite of the placebo response – a detrimental effect on health produced by psychological or psychosomatic factors such as negative expectations of treatment or prognosis

Attentional bias may also explain why some people with acute pain go on to develop chronic pain, while others do not. Vlaeyen et al. (1995) suggested that people who develop chronic pain in the absence of any clear physical injury or inflammation may respond to acute pain with a degree of fear, worry about its consequences and begin to check themselves for any pain sensations. Because they are now paying attention to a variety of aches and pains that may pass unnoticed in other people, they label their pain as symptomatic of an underlying problem. The long-term impact of this attentional bias towards pain-related stimuli, and related problems in disengaging from them is exemplified in a study by Lau et al. (2019). They identified three groups of young people aged 16–19 years; (i) those with no chronic pain, (ii) those with persistent pain that had minimal interference with their day-to-day life, and (iii) those with persistent pain which impacted significantly on their day-to-day life. In a study in which they were primed by being exposed to a pain or neutral face prior to a visual search task, they found that those in the third group evidenced a decrement in performance compared to both other groups on the task: a finding they took to indicate a problem disengaging from the pain-related stimulus. Further evidence of this process is provided by Dehghani et al. (2003). Their study, which used the dot probe task to explore attentional bias towards pain-related stimuli, found that people with chronic pain were more attentive to words describing the sensory experience of pain than neutral words or words describing its emotional or behavioural consequences. Their results also indicated that people with high levels of fear of pain both attended to relevant words more quickly and then had difficulty in re-focusing their attention away from them. Both results support the attentional hypothesis of chronic pain.

A number of theoretical models have elaborated on the role of attention in the experience of, and response to, pain. One example of this is Van Damme's motivational account of bias towards pain-related stimuli (see, Becker et al., 2018). This suggested we have an evolutionary bias towards automatically attending to pain, at the expense of paying attention to other goals; although as we reported earlier in the chapter, this bias may be overridden at times. In addition, they argued that the individual may consciously elect to prioritise attempts at pain control above other goals. With our limited attentional processing ability, this may mean increasing focus on pain reduction, and reduced attention to other life goals. A similar model was proposed by Eccleston and Crombez (1999) who identified three basic responses to pain. First, the presence of pain initiates escape-behaviours. Secondly, pain demands and captures attention. Thirdly, the ability of pain to capture attention and interrupt other ongoing activities is influenced by a number of characteristics of the pain: its intensity, novelty, and any emotion such as fear that it may be associated with. Pain interrupts other ongoing goal-related behaviour, with chronic pain resulting in the long-term interruption of attention towards other goals.


**Photo 16.1** The experience of pain differs according to context. Terry Butcher probably experienced no pain when clearly injured while playing football for England. After the match, it may have been a different story.

*Source*: David Cannon/David Cannon Collection.

## A psychobiological theory of pain

The evidence considered previously suggests that two sets of processes are involved in the experience of pain: one involving sensory information from the site of the painful stimulation, the other involving emotional and cognitive processes. The **gate control theory of pain** proposed by Melzack and Wall (e.g. 1965) takes both processes into account and is generally recognised as the best theoretical account of the experience of pain we now have. Melzack and Wall used the analogy of a gate to explain the pain experience. The essence of their gate control theory of pain is that the degree of pain we experience is the result of two sets of processes:

1. Pain receptors in the skin and organs transmit information about physical damage to a series of 'gates' in the spinal column (see Figure 16.1). Within the gates, these nerves link to other nerves along the spinal column that transmit information up to pain centres in the brain.
2. At the same time as we experience physical damage, we also experience related cognitions and emotions – fear, alarm, and so on. This information results in the activation of nerve fibres taking information from the brain down the spinal column to the gate at which the incoming pain signals enter the spinal column.

The degree of pain we experience is a result of differing levels of activation in these two systems. Activation of the sensory nerves from the site of the pain to the spinal column 'opens' the gate. This activates the nerves leading to the pain centres and is recognised as pain; that is, the essence of the biological theories of pain described above. However, the downward pathways activated by emotional and cognitive factors can also influence the position of the gate. Anxious thoughts or focusing attention on pain 'open' the gate and increase our experience of pain; calming or distracting thoughts 'close' the gate. This, in effect, inhibits neural impulses travelling up through the spinal cord to the brain and reduces the experience of pain. The intensity of pain we experience at any time is a function of these two sometimes competing and sometimes complementary processes.

**gate control theory of pain**

a theory of pain developed by Melzack and Wall in which a 'gate' is used as a metaphor for the chemicals, including endorphins, that mitigate the experience of pain

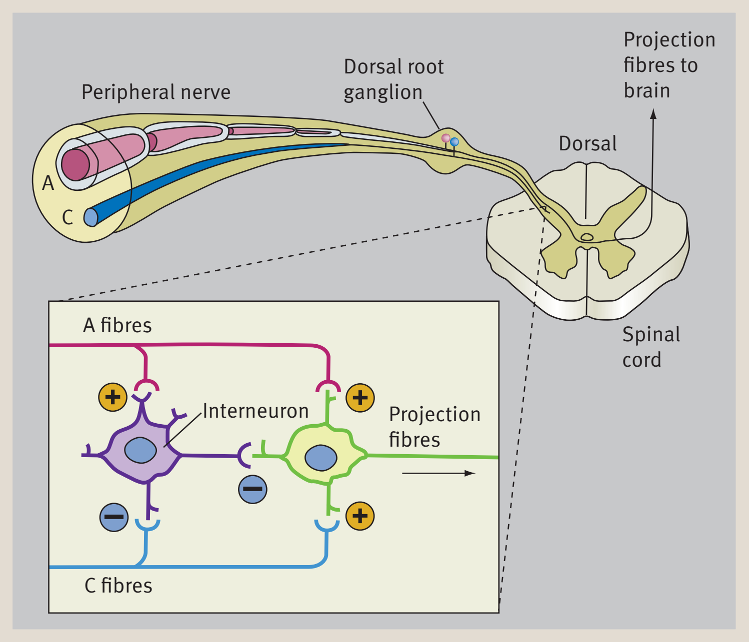


**Figure 16.1** The transmission of information along the A and C fibres to the gelatinosa substantia in the spinal cord and upwards to the brain

*Source*: Adapted from Rosenzweig, Leiman and Breedlove (1996: 272).

Pain sensations are transmitted from the site of an injury to the spinal gate by nerves known as nociceptors, three types of which have been identified:

- A delta fibres (types I and II):
  - respond to light touch, mechanical and thermal stimuli; carry information about brief sharp pain;
  - very strong noxious stimuli related to potential or actual damage to tissues; the experience is short-lasting.
- C polymodal fibres:
  - slow conducting; carry information about dull, throbbing, pain – which is experienced for a longer period than that from the A delta fibres.

Perhaps the most important characteristic of these different fibres is that they transmit information at different speeds. As a result, our response to injury usually involves two phases:

1. The first, mediated by A delta fibres, involves the experience of sharp pain.
2. This is followed by a more chronic throbbing pain mediated by the C polymodal fibres.

A second set of nerves, known as A beta fibres, also transmit tactile information, particularly related to gentle touch. These fibres can work to our advantage as they provide information that competes with the A delta and C fibres at the spinal column. When we receive an injury, activation of the A delta fibres is initiated and sends ‘pain signals’ via the spinal column to the brain. The first instinct we have following such an injury is to rub the site of the injury. This simple act reduces the amount of pain we experience. This occurs because rubbing the site of injury activates A beta fibres. Because they transmit information more quickly than C fibres, this information also reaches the brain more quickly and reduces the degree of activation that would have been triggered by the C fibres alone. In the terms of Melzack and Wall, activation of A beta fibres to touch and gentle stimuli can close the pain gate. Activation of A delta and C fibres to painful stimuli opens the gate.

The A and C fibres transmit information to areas in the spinal cord known as the substantia gelatinosa. These lie within the dorsal horn of each part of the spinal column (see Figure 16.1). Nerve impulses here trigger the release of a chemical known as substance P into the substantia gelatinosa. This, in turn, activates nerve fibres known as T(ransmitter) fibres, which transmit the sensation of pain to the brain:

- Information from A fibres is taken to the **thalamus** and on to the cortex, where the individual can plan and initiate action to remove them from the source of the pain.
- Information from the C fibres follows a pathway to the **limbic system** (and in particular the **amygdala**), **hypothalamus** and autonomic nervous system (see Chapter 8 ☛). Activity within the limbic system adds an emotional content, such as fear or alarm, to the experience of pain. The hypothalamus controls activity within the autonomic nervous system (see Chapter 8 ☛), which allows us to respond quickly to remove ourselves from harm.

The results of this neural activity are transmitted *down* the spinal column through nerve pathways known as reticulospinal fibres to the spinal gate mechanism (see Figure 16.2). These may trigger the release of a variety of chemicals into the ‘soup’ of chemicals in the substantia gelatinosa (and brain), the most important of which are naturally occurring opiate-like substances called

**thalamus**

area of the brain that links the basic functions of the hindbrain and midbrain with the higher centres of processing, the cerebral cortex; regulates attention and contributes to memory functions – the portion that enters the limbic system is involved in the experience of emotions

**limbic system**

a series of structures in the brain, often referred to as the ‘emotional computer’ because of its role in coordinating emotions; it links sensory information to emotionally relevant behaviour, in particular responses to fear and anger – includes the hippocampus, amygdala, anterior thalamic nuclei, septum and limbic cortex

**amygdala**

part of the limbic system involved in the processing of memory, decision making, and emotional responses (including fear, anxiety, and aggression); ometimes known as the ‘fear centre’ of the brain

**hypothalamus**

area of the brain that regulates appetite, sexual arousal and thirst. Also appears to have some control over emotions

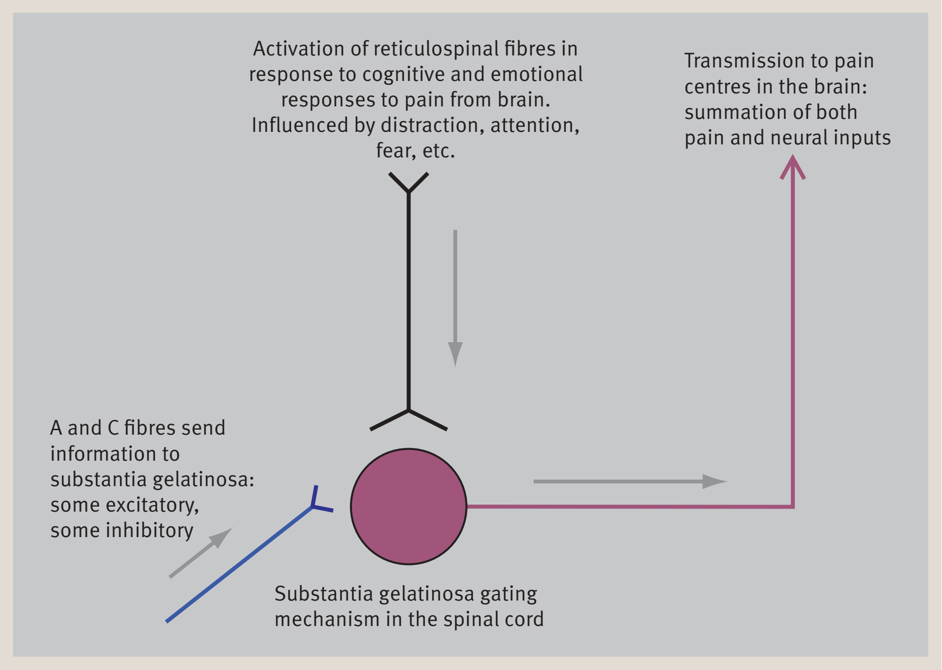


**Figure 16.2** A schematic view of the gate control mechanism postulated by Melzack and Wall

**endorphins**. These 'close' the gate and moderate the degree of pain experienced. Activity in this system is mediated by a number of factors, each of which influences the release of endorphins. These include:

- Focusing on the pain: worrying, or catastrophising, reduces the amount of endorphins released and opens the gate.
- Emotional and cognitive factors: feeling optimistic and unconcerned about the 'meaning' of the pain increases endorphin release and closes the gate – anxiety, worry, anger or depression opens the gate.
- Physiological factors: relaxation increases endorphin release and lessens the experience of pain.

Pain medication will also 'close' the pain gate.

**endorphins**

naturally occurring opiate-like chemicals released in the brain and spinal cord; they reduce the experience of pain and can induce feelings of relaxation or pleasure – associated with the so-called 'runner's high'

## WHAT DO YOU THINK?

We have already identified a number of factors that influence our experience of pain. Think how *you* react to pain. Do these factors reflect your own experience of pain? And how do we come to respond to pain in the way we do? Do you rub yourself if you are bruised to ease the pain? If so, why? Did you learn to do it as a response to previous pain experiences – or were you told to do so by a parent or friend? Are you stoic in the face of pain? If so, is this a result of how others have expected you to respond? 'Big boys don't cry': cultural and childhood experiences may encourage different ways of expressing both emotional and physical pain in men and women. Do they affect how you respond to pain? Or do you respond in ways determined by your personality? People who are generally anxious may be more prone to respond to pain with catastrophic thinking, anxiety and high levels of physiological arousal – resulting in a relatively high experience of pain (and other labelling of bodily sensations as 'symptoms' of disease: see Chapter 9 (☛). People who are more relaxed and optimistic may have a less emotional response to pain and experience relatively less pain. Is this the case for you?

# The neuromatrix

Despite the success of the gate theory of pain, it has still struggled to account for phantom limb pain: pain in the absence of stimulation by the A and C fibres. In response to these limitations, Melzack (2005) has developed a more complex theory of the mechanisms of pain that attempts to explain this mysterious phenomenon. His model has three key assumptions:

1. The same neural processes that are involved in pain perception in the intact body are involved in pain perception in the phantom limb.
2. All the qualities that we normally feel from the body, including pain, can be felt in the absence of inputs from the body.
3. The body is perceived as a unity and is identified as the 'self', distinct from other people and the surrounding world.

Melzack contended that the anatomical substrate of the 'body-self' is a large, widespread network of neurons linking the thalamus, cortex and limbic system in the brain. He termed this system the 'neuromatrix'. We process and integrate pain-related information within the neuromatrix. Related information about a pain experience (physical elements of the injury, emotional reactions to the injury, and so on) combine to form a 'neurosignature' or network of information about the nature and emotional reaction to a pain stimulus. Neurosignatures have two components:

1. *the body-self matrix*: processes and integrates incoming sensory and emotional information;
2. *the action neuromatrix*: develops behavioural responses in response to these networks.

Behavioural responses to pain can only occur after information about the nature of the pain, its cause, and physical and emotional consequences have been, at least, partially processed and integrated. We do not move away from a hot object, for example, until we realise that it is the cause of pain and that continuing to be near it will cause further pain and potential injury. We only become consciously aware of pain after this integrated network of information is then projected to what Melzack terms the 'sentient neural hub': the seat of consciousness. Here, the stream of nerve impulses is converted into a continually changing stream of awareness.

So far, Melzack's theory does not explain the experience of phantom limb pain. This moves us from an explanation of how we feel pain from external sources to one explaining how we feel pain generated by the body itself. Melzack suggested that the neuromatrix is pre-wired to 'assume' that the limbs can move. Accordingly, in people who have had limbs removed, the body still sends signals to try to move them. When they do not move in response to these signals, stronger and more frequent messages may be sent to the muscles, and these are perceived as pain. Melzack's theory of pain is still relatively new and has only recently been subjected to empirical research. However, what data there are provide broad support for the existence of a neuromatrix, but we have yet to locate it within any particular brain area (Derbyshire, 2000). That said, not all the phenomena of phantom limb pain can be explained by the neuromatrix. In particular, it fails to explain why the reduction or elimination of other sensations associated with the experience of the phantom limb is not accompanied by reductions in pain, how phantom limb pain can spontaneously cease, and why not all patients experience this type of pain (Giummarra et al., 2007).

# Helping people to cope with pain

The first-line treatment for *acute* pain is generally some form of pharmacological treatment – varying in strength from aspirin to some form of opium derivative such as pethidine. Psychological interventions generally form a second-level intervention. The American Agency for Health Care Policy (1992), for example, suggested that these should be used for those who find this type of intervention 'appealing', where patients may benefit from reducing or avoiding pharmacological treatment, have high levels of anxiety, would need prolonged pain relief and/or who have incomplete pain relief following pharmacological intervention. By contrast, increasing numbers of patients with *chronic* pain resulting from conditions as varied as rheumatoid arthritis and lower back pain are being taught to manage their pain using psychological approaches in order to minimise the amount of painkilling medication they need to take and to maintain or improve their quality of life. It is important that the effectiveness of these interventions is evaluated as part of the day-to-day care of patients as well as in research studies. So, before we look at some of the approaches used to treat both acute and chronic pain, we examine some simple, and not so simple, ways of measuring pain.

## Measuring pain

The simplest measure of pain involves the use of a simple linear visual analogue or numerical rating scales – typically varying from a score of 0, registering no pain, to 100, rating the most pain you could imagine. This type of measure is quick to administer and score and is frequently used in clinical settings. A limitation of the approach is that patients often find it quite difficult to consider pain in numerical terms. Another simple approach involves patients rating their pain on a series of adjectives denoting increasing pain: mild, distressing, excruciating, and so on. This has the advantage of being more easily comprehensible to patients than numeric scales – it uses concepts patients are more familiar with. However, this approach has its disadvantages, as many patients tend to rate themselves somewhere in the middle of such scales, making them less sensitive to subtle differences in pain than analogue scales.

One important limitation of these measures is that they simply measure the sensation of pain. However, we have already noted that the experience of pain is multidimensional. It involves emotional, cognitive, and behavioural responses as well as sensory experiences. A number of measures have tried to address these inadequacies. Perhaps the best known of these is the McGill pain questionnaire (e.g., Melzack, 1975). This is more complex to administer and interpret than the simple scales described above. However, it provides a multidimensional understanding of the nature of the pain that an individual is experiencing. In its various forms, it measures:

- the type of pain: including throbbing, shooting, stabbing, cramping, gnawing, hot and tender, using a four-point scale from ‘none’ to ‘severe’;
- the emotional response to the pain: including tiring, exhausting, fearful and punishing;
- the intensity of the pain: on a scale from ‘no pain’ to ‘worst possible pain’;
- the timing of pain: whether it is brief, continuous or intermittent.

While this measure extends our assessment of pain, it does not address all the responses to it. It does not, for example, measure pain in relation to movement or measure an individual’s behavioural response to pain. How much does it restrict their daily life? Can they walk upstairs, or lift heavy weights? These may all have to be measured separately. To remedy these deficits, Turk and Okifuji (1999) suggested that one can also measure:

- verbal/vocalisations: sighs, moans, complaints;
- motor behaviour: facial grimacing, distorted gait (limping), rigid or unstable posture, excessively slow or laboured movement, seek help/pain reducing behaviour;
- treatment behaviours: taking medication, use of protective device (e.g. cane, cervical collar), visit doctor;
- functional limitations: resting, reduced activity.

Each of these may become a target for some of the interventions discussed below.

## Treating acute pain

A number of approaches have been used to help people to cope with acute pain. Any such procedures used need to be relatively easy to learn and use. Accordingly, most approaches to acute pain control have focused on:

- increasing patients’ sense of control over the pain experience and medical procedures that may be causing the pain;
- teaching coping skills, including distraction techniques and relaxation;
- hypnosis.

Some of these are discussed further in the context of preparing people for the experience of surgery in Chapter 10 ☛. Here, we address other ways of achieving these goals.

### Increasing control: patient-controlled anaesthesia

The experience of pain following trauma or surgical operations can be made worse by patients’ fears that they cannot control their pain. They may be frightened that when they are in significant pain the nurses may be too busy to give them painkillers, that the pain will be so bad that it will not be controlled by the type of painkiller they will be given, and so on. To alleviate such fears, patients may exaggerate reports of pain or pester healthcare professionals to give them painkillers in order to avoid periods of inadequate analgesia. This may result in them experiencing unnecessary anxiety and using more medication than necessary.

One way that each of these issues can be addressed is through the use of **patient-controlled analgesia (PCA)**. Using this method, the patient controls how much analgesic drug they receive through an intravenous drip – albeit with some controls built into the delivery system so they cannot exceed a specified dosage. It is assumed that because patients can control the timing of their pain relief, they will be less anxious about the control of their pain, be more satisfied with their analgesia and use less analgesic. Systematic reviews of this approach (e.g. Morlion et al., 2018) suggest that this is the case, and its use has even been advocated in patients with a pre-existing opioid dependency as the overall amount of drug delivered by the system can be appropriately limited (Mehta and Langford, 2006). Children can also use PCA systems, usually with good outcomes, although care needs to be taken to avoid a range of risks in children, including those related to errors by: (i) the child (e.g. overuse with risk of opioid-related respiratory problems); (ii) others, including parents (e.g. inappropriate and excessive use); and even, (iii) professionals (e.g. failure of adherence to protocols) (see Ocay et al., 2018).

## Teaching coping skills

### Distraction

We have already noted in the chapter that focusing on pain tends to increase the experience of pain, while distraction decreases it. Given the apparent simplicity of teaching distraction techniques, these would seem to be sensible strategies to teach patients who are in acute pain or who have to undergo painful procedures. The procedure seems to work. Callaghan and Li (2002), for example, taught women undergoing a hysterectomy to distract themselves from worrisome thoughts prior to their operation. Compared with women only given information about the procedure, they reported less pain and evidenced less distress after the operation. Distraction may be more effective than alternative medical interventions in some cases. Balanyuk et al. (2018), for example, found distraction to be more effective than local anaesthetic cream in reducing pain during insertion of a peripheral venous catheter line. More widely, Dancel, Liles and Fiore (2017) concluded that active distraction is highly efficacious, and more so than passive distraction, in the management of a range of painful medical procedures in young people. At its most cutting edge, there is increasing evidence that the levels of immersion achievable through the use of virtual reality can be powerful moderators of pain in both long-term conditions such as fibromyalgia, phantom limb pain, and the excruciating pain of dressing burns injures, as well as during acute medical procedures, although the responses to this approach are highly idiosyncratic and not all patients are likely to benefit (Pourmand et al., 2019).

**patient-controlled analgesia (PCA)**
a technique through which small doses of analgesic drugs, usually opioids, are administered (usually by an intravenous drip and controlled by a pump) by patients themselves; it is mostly used for the control of postoperative pain

### Relaxation

A range of relaxation approaches to minimise pain have been assessed. Felix et al. (2019), for example, reviewed evidence of the effectiveness of interventions as varied as relaxation exercises, meditation, 'soothing biorhythmic music' and hand and foot massage in the remediation of post-operative pain, and found limited evidence of their overall benefit. However, within this wider group of interventions, there have been a number of successful trials involving teaching people to relax the muscles throughout their body, particularly those close to the site of the pain (see Chapter 13 ☛). This has a number of advantages. First, it can be used to reduce any muscular tension that can contribute to the experience of pain. Secondly, because relaxation instructions may explicitly involve thinking about pleasant images or at least images inconsistent with the painful situation, it may act as a form of distraction. The concentration involved in relaxing may also distract from pain sensations. Finally, there is evidence that relaxation promotes endorphin release and thus has a direct impact on the pain experience.

Examples of relevant research include work by Vagnoli et al. (2019), who found muscle relaxation combined with guided imagery involving pleasant memories to be effective in reducing both anxiety and pre-operative pain in children undergoing minor surgery. Similarly, Friesner et al. (2006) found that muscle relaxation combined with the use of opiate drugs was superior to opiate drugs alone during a short but painful surgical procedure involving removal of a tube inserted into the chest during coronary artery bypass surgery. Evidence in relation to mindfulness (see Chapter 13 ☛) is promising, but it is too early to come to definitive statements concerning its value in managing pain (Lachance and McCormack, 2019).

#### Hypnosis

Hypnosis is a procedure through which a health professional or the individual can induce a hypnotic state during which they can experience changes in sensations, perceptions, thoughts or behaviour. Although there are many different hypnotic inductions, most include suggestions for relaxation, calmness and wellbeing. Instructions to imagine or think about pleasant experiences are also commonly included in hypnotic inductions. It has been shown to have a reliable and significant effect on acute pain. One of the most painful, repeated, medical procedures involves treating burn wounds, and remediation here can frequently involve the use of opiate or similar medication. The consensus finding that hypnosis can reduce pain intensity (and anxiety) in people undergoing this procedure is therefore encouraging and may reduce the need for opiate use (Provençal et al., 2018).

Not only can hypnosis reduce pain, but it may also aid patients' physical recovery. Ginandes et al. (2003), for example, examined the effects of hypnosis on pain and wound healing following breast surgery. They allocated women to three interventions following surgery: usual care (normal analgesia); sessions with a counsellor providing unstructured support; and hypnosis, in which they focused on relaxation and 'accelerated wound healing' as part of the instructions ('Imagine your wound healing well'). They measured the women's pain and level of wound healing one week and seven weeks following the interventions and found that the wounds of the women in the hypnosis condition healed significantly more quickly than those in the others. They also experienced less pain over the course of their recovery. Hypnosis can also work in the long-term. Brugnoli et al. (2018) followed a cohort of patients with severe chronic diseases experiencing rheumatic, neurological and cancer-related pain for a period of up to two years following learning the use of self-hypnosis to control their pain. At both one- and two-year follow-up, patients who learned self-hypnosis as an adjunct to their medication reported less pain than those in a control condition receiving standard treatment using opioid medication and used significantly less medication to achieve these benefits.

The benefits of self-hypnosis need not be restricted to adults. Liossi et al. (2009) provided an example of the use of hypnosis in the control of pain during venipuncture (blood taken through a needle from a vein) in children aged between 6 and 16 years. The children were taught self-hypnosis techniques involving images including a switch to modulate the experience of pain, feelings of numbness, and the experience of anaesthesia across the hand. They were then encouraged to use this approach up to an hour before having their blood taken. Those who received the hypnosis intervention experienced less anticipatory anxiety as well as less pain during the procedure itself. So effective has this approach been, Loeffen et al.'s (2020) expert group's practice guidelines recommended the use of hypnosis (and active distraction) in all needle procedures involving children.

## Treating chronic pain

### Transcutaneous electrical nerve stimulation (TENS)

Before examining psychological interventions to reduce pain, we first consider a popular method of pain control, based on the electrical stimulation of A beta fibres in order to compete with the pain signals of pain-related nerves (see discussion earlier in the chapter) and stimulate C fibres to result in endorphin release. Transcutaneous electrical nerve stimulation (TENS) involves the use of a small electrical device connected by wires to electrodes placed on the skin in the area of the pain. This allows a small, low-intensity electric charge to be passed across the area. Such stimulation devices are typically used for between 15 to 20 minutes, several times a day, and are controlled by the user. A search through a number of UK National Health Service health providers websites indicates wide use of TENS for managing pain throughout their hospitals, although the NHS website itself (NHS, 2018) is more guarded in its recommendations noting a lack of reliable evidence to support its use. Indeed, much of the evidence related to TENS is so poor, it fails to provide a good basis for making judgements about its value and justifying its use. As an example of this research, Al-Smadi et al. (2003) reported that TENS was no better than placebo in the treatment of low back pain in people with multiple sclerosis. However, they randomly allocated only five people to each treatment group – making any statistically significant treatment effect almost impossible to find. As a consequence of this limited evidence base, Johnson et al. (2017) found they could come to no conclusion about the effectiveness of TENS as a stand-alone treatment for fibromyalgia, Gibson et al. (2019) found no evidence of either benefit or harm in the treatment of chronic pain, while Claydon et al. (2011) concluded there was strong evidence of a lack of effectiveness in all types of pain other than that associated with pressure.

## Relaxation and biofeedback

Relaxation can be used to relax the whole body or to relax specific muscle groups such as those on the forehead or back, which contribute to headaches and back pain, respectively. The latter may be of particular benefit in some patients. Anecdotal evidence (Turk, personal communication), for example, noted that many patients who were taught general relaxation for the treatment of back pain reported reductions in pain. However, one small subgroup of individuals reported either no benefit or even increased pain following the intervention. Closer assessment revealed that, while many people in this group had been able to relax most of their muscles, they had been unable to relax the particular muscles in their back that were contributing to their pain. To do this, they needed guidance on relaxing these specific muscles. This can be achieved through the use of **biofeedback** techniques, including electromyographic biofeedback, galvanic skin response and thermal biofeedback:

- *Electromyographic (EMG) biofeedback*: measures the small amount of electrical current in the muscles. The voltage equates with muscle tension: higher voltage = higher tension. Uses electrodes stuck to the skin over specific muscles that contribute to pain and provides the most direct and accurate form of feedback.
- *Galvanic skin response (GSR)*: measures general tension in the body by measuring subtle changes in the moisture (sweat) typically of the hand. Increased sweat relates to increased general muscle tension – although the relationship is far from one-to-one.
- *Thermal biofeedback*: based on a theory that warming the skin can reduce the pain of headaches. Skin temperature is measured by a thermistor, often placed on the back of the fingers to avoid sweat and to provide a more accurate gauge of body temperature.

biofeedback

technique of using monitoring devices to provide information regarding an autonomic bodily function, such as heart rate or blood pressure; used in an attempt to gain some voluntary control over that function

Whatever the technical approach, biofeedback helps patients make changes (relax, increase finger temperature) guided by some form of feedback of the magnitude of any physiological changes they produce. In the case of auditory feedback, for example, a tone may become lower as the person relaxes their muscles. Visual feedback may involve moving an indicator along a scale as they do the same. In this way, changes in muscle tension that the patient may not recognise without feedback are made apparent and they can learn how to improve and replicate the response.

One particular condition in which biofeedback has been used with notable success is in the treatment of chronic headaches as this typically involves relaxation of specific muscles involved in their initiation. In an overview of all relevant research, Lee et al. (2019) conducted a meta-analysis of all psychological interventions used to treat headache disordered patients, including biofeedback, cognitive behaviour therapy (see section later in this chapter) and mindfulness meditation. Overall, they found significant benefit from all these interventions on measures of headache days per month, headaches per week, and headache severity. No differences in the effectiveness of any particular intervention were found. Gains following biofeedback of around 35 to 55 per cent reductions in frequency and severity of in migraine and tension-type headaches are typical (Rains et al., 2005). These improvements are about three times as large as any gains following some form of placebo intervention, and the equivalent to gains achieved by medication.

So effective is biofeedback in the treatment of tension headache, the European Federation of Neurological Sciences (Bendsten et al., 2010) guidelines recommended its use, noting at the same time that cognitive behavioural interventions and relaxation are also ‘likely’ to be effective. Biofeedback when used in at least some other specific pain contexts has also proven at least equally effective as other non-pharmacological interventions. Tan et al. (2015), for example, found it to be as effective is hypnotherapy in the treatment of chronic low back pain on measures of pain intensity, pain-related interference with day-to-day activities, and quality of sleep.

## Behavioural interventions

The first modern psychological intervention for pain involved behavioural interventions, based on operant conditioning processes. The treatment model, initially developed by Fordyce (1976), was based on the premise that we cannot truly understand the pain experience of others; all we can do is observe 'pain behaviour'. Fordyce argued that this behaviour should, therefore, form the target of any intervention, not the unobservable inner experience. Operant theory states that pain behaviour may be established and controlled not only by the experience of pain but also by how others respond to expressions of pain. Pain behaviour may be as subtle as a gentle wince or as obvious as lying down unable to move as a result of apparently unbearable pain. It may be reinforced by expressions of sympathy, being 'let off' tasks about the home, given analgesia, and so on (see Bokan et al., 1981, earlier in the chapter).

The aim of behavioural interventions is to reduce disability by changing the environmental contingencies that influence pain behaviour – to remove the individual from any reinforcement of their pain behaviour. Instead, non-pain-related, adaptive behaviour is reinforced. The methods used include:

- reinforcement of adaptive behaviour such as appropriate levels of exercise;
- withdrawal of attention or other rewards that were previous responses to pain behaviour;
- providing analgesic medication at set times rather than in response to behaviour.

In this way, new forms of behaviour are encouraged through appropriate reinforcement, and older maladaptive behaviour is extinguished through non-reinforcement. The approach may involve both health professionals and others with whom the patient interacts, including their partner or even friends.

**Photo 16.2** Biofeedback has proven to be an excellent treatment for specific pain due to muscle tension such as headache. However, in many cases, simple relaxation may prove as effective

*Source*: BatuhanPehlivan/Shutterstock.

Depending on the nature of the presenting problem, these processes may be augmented by other interventions. In the case of lower back pain, for example, where disuse may have resulted in a weakening of the back muscles, patients may take part in exercise programmes. In these, patients will typically engage in a number of exercise trials to identify their tolerance for various lifting activities and movements. The programme will then advance them through a series of progressively more difficult steps towards full mobility and strength. Success at each stage of the intervention is positively rewarded by the healthcare professionals involved in the treatment programme.

Early studies of this approach were often case histories, as the approaches used to treat individual cases were necessarily quite different. Fordyce (1976), for example, reported a case in which they moved a hospital patient showing excessive pain behaviour into a single room, the door of which could be closed if necessary. This prevented the patient trying to attract the attention of nurses in the ward. Rewards for non-pain behaviour and 'punishments' for pain-related behaviour were achieved by entering and leaving the room if the patient inappropriately demanded pain medication or staying for social chat if they did not do so. These various case reports indicated the potential for this type of treatment. More recently, the development of standardised behavioural programmes in the treatment of a variety of disorders, including back pain, has meant that their effectiveness can be assessed using group designs. Back pain is frequently, and successfully, treated using behavioural methods, possibly because it is a common disorder that often has no obvious pathology, but which can cause significant impairment. Van Tulder et al. (2003), for example, reported a meta-analysis of the effects of behavioural programmes on lower back pain, and concluded that there was strong evidence that behavioural treatments were of significant benefit on measures of reported pain, improvements in mobility and lifting capacity, and on behaviour away from the clinic. Despite these successes, though, the wider shift from behavioural to cognitive-behavioural interventions has been mirrored within pain treatment programmes, which now often combine behavioural and cognitive elements.

## Cognitive-behavioural interventions

Behavioural interventions clearly work by changing behaviour, but these changes may also influence other parts of the pain experience. Active engagement in activities may distract patients from negative cognitive and emotional responses to pain. Re-engaging in previously impeded activities may increase self-efficacy beliefs and optimism ('Wow – I didn't think I was going to be able to do that. Perhaps I can do some other things I've stopped doing'). That is, behavioural programmes may *indirectly* change pain-related cognitions, and these changes may contribute to any improvements that patients make. Cognitive-behavioural approaches tackle these issues more directly. They focus on the cognitions mediating our emotional and behavioural responses to pain. Cognitions are seen as central to our experience of pain, and our reactions to it. As such, the model does not contradict the model of pain provided by the gate control model – it focuses on one group of variables that influence the gate. The goals of cognitive-behavioural therapy (CBT) for pain are threefold:

1. To help patients alter their beliefs that their problems are unmanageable. To help them to become 'resourceful problem solvers' and move away from feeling unable to cope with their pain.
2. To help patients identify the relationship between their thoughts, emotions and behaviour, and in particular how catastrophic or other negatively biased thoughts can lead to increased perceptions of pain, emotional distress and psychosocial difficulties.
3. To provide patients with strategies to manage their pain, emotional distress and psychosocial difficulties, and in particular to help them to develop effective and adaptive ways of thinking, feeling and behaving.

Cognitive-behavioural interventions can take the form of both individual and group interventions. Cognitive change is brought about in a number of stages (see also the discussion of stress management skill in Chapter 13 ☛). In these, patients are helped to identify any maladaptive thoughts that are increasing their experience of pain or their disability. This can be achieved by discussion in therapy sessions in which patients reflect back on periods of pain or when they have been frightened to engage in particular behaviour. Any thoughts that occurred at such times are identified and discussed. Patients may also be asked to monitor their thoughts during their day-to-day activities by completing a diary in which they record their level of pain, accompanying thoughts and mood.

Once patients have begun to identify how their thoughts influence the level of pain they experience, their behaviour and their mood, they are taught to change their nature to more adaptive ones. This may involve two types of cognitive intervention. The first is known as self-instruction training. In this, patients are taught to change the commentary in their head at times of worry or concern about their pain or activities to a more positive commentary. This can be pre-rehearsed and thought through with the therapist. Such thoughts include reassuring commentaries, such as: 'I've had pain like this before and it didn't do me any harm in the long run' or 'The pain only means I'm extending myself, not doing myself any damage'. Other thoughts may involve reminders to use other strategies to help to control the pain: 'OK! When the pain starts, remember to relax so I don't add to it with tension', and so on.

A more complex cognitive process involves trying to identify the thoughts that are driving any emotional distress or inhibiting behaviour and challenging them. This involves treating them not as truths but as hypotheses and challenging the hypotheses by looking for contrary evidence. In practice, these types of challenge may not be that different to the self-instructions, but they may be more targeted at particular worries or concerns:

> Oh no! My back's beginning to hurt again. I know that means I'm going to be in pain for hours – I'd better stop now and take it easy. Hang on! Remember the last time this happened; I didn't feel that bad, particularly after relaxing and slowing down a bit. So, take it easy – keep going . . . I'll feel better in myself for trying.

These cognitive interventions are often accompanied by a programme of gradually increasing exercise. This may have a number of advantages. First, and most obviously, it will increase fitness and minimise restriction of activities. In addition, it allows patients to learn from their own experience that they will not be harmed by the pain they are experiencing. Cognitive change has been shown to be an important mediator of change in therapy. Burns et al. (2003), for example, found that the cognitive changes patients made in the early stages of a cognitive-behavioural programme were strongly predictive of pain outcomes later in therapy. They took measures of catastrophising and pain at the beginning, end and middle of a four-week cognitive-behavioural pain management programme. Early changes on the measure of catastrophising were predictive of pain measures taken at the end of therapy. By contrast, early changes in pain did not predict changes in catastrophising. Turner et al. (2007) came to similar conclusions using data from patients with **temporomandibular disorder pain** (a form of facial pain). In this group, changes in pain beliefs (control over pain, disability and pain signals harm), catastrophising and self-efficacy in relation to managing pain mediated the effects of cognitive-behavioural therapy on pain, activity interference and jaw-use limitations one year following the end of therapy.

Hanson and Gerber (1990) summarised a number of strategies for coping with periods of particularly intense pain that can be taught in a cognitive-behavioural programme, including:

- stop and ask myself if I can identify the pain trigger or learn anything from this pain;
- begin slow, deep breathing and remind myself to keep calm; review my alternatives;
- identify some distracting activities – a conversation with my partner about anything but the pain, a crossword puzzle, baking biscuits, etc.;
- take a long, hot shower;
- listen to relaxation or self-hypnosis tape;
- use positive self-talk – 'The pain won't last. I can handle this on my own';
- use pain-modification imagery – 'Imagine a block of ice resting on my back, see my endorphins working to counter the pain', and so on.

This section has been a long one, reflecting the wide use of cognitive behavioural interventions in pain clinics throughout the world. It is therefore somewhat disappointing to consider some of the evidence related to its effectiveness. Williams, Eccleston and Morley (2012), for example, analysed data from 35 studies with nearly 5,000 participants, and found no evidence of the effectiveness of behaviour therapy, and that while cognitive behaviour therapy was significantly more effective than no treatment on measures of disability, catastrophising, disability and mood in the short- but not long-term, there was little evidence of any advantage when compared with

**temporomandibular disorder pain**

a variety of conditions that cause tenderness and pain in the temporomandibular joint (hinge joint of the jaw) active or placebo interventions. More recently, Knoerl, Smith and Weisberg (2016) found that of the 35 studies they reviewed less than half (43 per cent) found significant reductions in pain following CBT treatment for chronic pain.

The addition of cognitive elements to the basic behavioural programmes may also be of less benefit than was originally expected. Schemer et al. (2019), for example, compared a basic behavioural programme, in which individuals with chronic back pain gradually increased the amount of activity they engaged in and worked through a hierarchy of re-engagement with previously avoided contexts, with a more complex cognitive behavioural programme and found no differences in their effectiveness. These findings are in keeping with a number of so-called third wave therapies (see Chapter 13 ☛) that have returned to core behavioural interventions and actively argued against the need for specific strategies of cognitive change. It is possible these simpler interventions may be of equal or even more benefit as people experiencing pain may lack the motivation to engage fully with complex cognitive behavioural programmes.

Other factors may also interfere with the effectiveness of complex interventions such as CBT. Bair et al. (2009) found a number of other factors associated with low adherence including: lack of support from friends and family, limited resources, depression, ineffectiveness of pain-relief strategies, time constraints and other life priorities, physical limitations and poor patient-physician relationships. While adherence to any programme may be less than ideal, those that do adhere to programmes even when waiting for medical treatment do appear to benefit (McCracken, Sato and Taylor, 2013). Perhaps future research needs to consider not just whether cognitive behaviour therapy for pain effective, but who benefits most from it.

## Mindfulness-based interventions

As mindfulness-based interventions are becoming increasingly used in mental health settings, so they are in physical health settings – and with consistent effects. Hilton et al.'s (2017) meta-analysis of 38 studies of the impact of mindfulness found evidence of modest but consistent reductions in pain, as well as gains on measures of depression and quality of life.

An interesting study was reported by Rosenzweig et al. (2010), who compared the effectiveness of mindfulness training in patients with a number of different types of pain and found marked differences in effectiveness. Most patients, with conditions as varied as back, and neck pain, showed gains on measures of pain intensity and functional limitations. Patients with fibromyalgia, or tension or migraine headaches reported minimal benefit, while those with arthritis reported the greatest improvements. Zautra et al. (2008) made a direct comparison of CBT and mindfulness in a group of patients with rheumatoid arthritis. Their outcome measures included a measure of pain and inflammation (interleukin-6). Overall, those

### Case history: Mr W

I came to this clinic [for cognitive-behavioural therapy] after years of looking for a treatment for my back pain. The doc sends you here, there, everywhere looking for the answer. I've had pain killers, TENS, physiotherapy, manipulation . . . and then surgery. Every time you go to the next treatment, you have that little ray of hope that this will provide the cure! I've even gone to the alternative people in the hope that they would help. The weirdest thing I have had was something called cranial manipulation . . . supposed to relieve the nerves or something. But every one you hope the pain will go . . . even if you don't believe it quite as strongly with different treatments! But this has been different. Rather than trying to take the pain away, the course has focused on helping me cope with the pain. That was the first shock on the course – and it was disappointing. I expected that you could get rid of it, not keep it . . . and let me cope better! I was quite depressed for a few days when I learned this . . . but I guess I had to stick it out. I don't have much choice. But I must admit, as the course has gone on, it has helped. The relaxation really helps me. I can take myself away from the pain for a while if I imagine stuff. And at least I know I can cope with the pain, and won't let it stop me doing things like I used to . . .

in the CBT group achieved the greatest changes in both measures. However, patients with a history of recurrent depression achieved greater changes on measures of joint tenderness and mood following the mindfulness training than did those in the CBT group. By contrast, Davis et al. (2015) found that while mindfulness and CBT appeared to be of equal benefit in reducing pain, mindfulness proved superior in reducing catastrophic beliefs about the nature and implications of pain, morning disability, and fatigue. Despite these nuanced differences across differing populations, the overall picture is that gains following mindfulness-based interventions appear to be comparable or greater than those achieved by CBT (Veehof et al., 2016).

Some researchers have evaluated innovative strategies to provide mindfulness-based interventions – in ways that are both effective and cost-effective. In one such study, Gardner-Nix et al. (2008) compared a mindfulness chronic pain intervention delivered using a group face-to-face format with the same intervention using a videoconferencing facility to patients in their own homes. Outcomes of these two active interventions were compared to those of a waiting list control group. Both groups made more gains on a measure of pain than those in the control condition. However, those who received the face-to-face intervention scored more highly than the remote group on measures of 'usual pain'. A second innovative approach was adopted by Johnston et al. (2008), who examined the impact of a self-help book related to Acceptance and Commitment Therapy (see Chapter 13 ☛). Participants read the book and completed related exercises over a period of six weeks, with the support of weekly telephone calls. The intervention had a modest impact on pain, while also resulting in greater changes in acceptance, quality of life, and satisfaction with life.

## RESEARCH FOCUS

### A direct comparison of two psychological approaches to pain management

Cherkin, D.C., Sherman, K.J., Balderson, B.H. et al. (2016). Effect of mindfulness-based stress reduction vs cognitive behavioral therapy or usual care on back pain and functional limitations in adults with chronic low back pain: a randomized clinical trial. *Journal of the American Medical Association*, *315*: 1240–1249.

### Introduction

This interesting study provides a direct comparison of two of the most popular psychological approaches used in stress and pain management. They come from different theoretical backgrounds, with the cognitive behavioural therapy (CBT) approach focusing on the identification and challenge of thoughts that exacerbate the pain/stress experience, while mindfulness aims to reduce their impact by preventing them becoming the focus of attention, but not directly challenging them. The mindfulness intervention as provided in this study incorporated the practice of yoga, itself beneficial for back pain. On this basis, the researchers predicted this would be the most effective intervention.

### Method

#### *Participants*

Participants were 342 people aged between 20 and 70 years old, recruited via a large healthcare provider, experiencing non-specific low back pain lasting at least 3 months. Potential participants were excluded if they rated pain' bothersomeness' less than 4 or' pain interference with activities' less than 3 on 0- to 10-point scales.

#### *Randomisation and conditions*

Following providing consent and completion of baseline measures participants were randomly allocated to one of three conditions, each lasting 2 hours per week over

*(continued)*

an 8-week period (plus a voluntary workshop day for the MBSR group):

- *Mindfulness-based Stress Reduction (MBSR)* followed the basic format of the Kabat Zinn programme (see Chapter 13 ☛). It did not focus specifically on managing pain but taught a range of techniques to increase participants' mindfulness, including body scan, yoga, and various forms of meditation including sitting meditation with awareness of breathing, and walking meditation.
- *Cognitive Behaviour Therapy* (CBT) techniques included, (i) psychoeducation including the relationships between thoughts and emotional and physical reactions, sleep hygiene, relapse prevention, and (ii) instruction and practice in changing dysfunctional thoughts, establishing and working toward behavioural goals, relaxation skills, activity pacing, and pain-coping strategies.
- *Usual care* involved provision of any medical care required, but no additional support.

Each intervention was led by trained therapists experienced in the approach they were teaching and followed a manual to ensure consistent delivery. In addition, sessions were recorded and monitored to ensure adherence to the required therapeutic approach.

### *Measures*

- *Roland Morris Disability Questionnaire (RDQ)*: measured back-pain related functional limitation.
- *'Back pain bothersomeness'* was measured on a 0-10-point scale.
- *Patient Health Questionnaire – 8 (PHQ-8)*: measured depressive symptoms.
- *Generalised Anxiety Disorder Scale (GAD-2)*: measured anxiety.
- *Patient Global Impression of Change scale*: rated perceived improvement in pain on a 7-point scale.

Measures were taken at baseline, mid- and end-treatment (4, 8 weeks), and 26 and 52 weeks.

## Results

Analysis followed an intention to treat model, in which data from all participants is included in the analysis. If participants drop out of the study, their baseline data is added to the database at each time point they miss (i.e. they are assumed to make no gains or losses on any measure). This provides strong statistical power, and a relatively conservative assessment of change, compared to studies that just analyse data from completers. Here, data from baseline, 8, 26 and 52 weeks is reported. The data take two forms: the percentage of participants in each group to make clinically significant gains on key measures and the 'relative risk' of gains in each group versus the others.

On the key pain-related outcome measures, the overall pattern was one of benefit from being in either the CBT or MBSR group, with modest or no differences

**Table 1** changes in pain-related outcome measures

| | Percent to achieve clinically relevant change | | | | Relative risk | | |
|---|---|---|---|---|---|---|---|
| Week after baseline | Usual care | MBSR | CBT | P value | MBSR v usual care | CBT v usual care | MBSR v CBT |
| RDQ | | | | | | | |
| 8 | 27.3 | 34.5 | 24.7 | NS | 1.34 | 1.47* | 1.10 |
| 26 | 35.4 | 47.4 | 51.9 | .04 | 1.37* | 1.31* | .95 |
| 52 | 48.6 | 68.6 | 58.8 | .01 | 1.41* | 1.21 | .86 |
| Pain bothersomeness | | | | | | | |
| 8 | 24.7 | 36.1 | 33.8 | .15 | 1.46 | 1.37 | .94 |
| 26 | 26.6 | 43.6 | 44.9 | .01 | 1.64* | 1.69* | 1.03 |
| 52 | 31.0 | 48.5 | 39.6 | .02 | 1.56* | 1.28 | .82 |
| | | Change estimates | | | | Between group differences | |
| Change pain intensity | | | | | | | |
| 8 | –.09 | –1.00 | –.86 | .002 | –.63* | –.49* | .15 |
| 26 | –.65 | –1.10 | –1.15 | .04 | –.45* | –.50* | –.05 |
| 52 | –.79 | –1.42 | –1.40 | .007 | –.63* | –.61* | .02 |

* P < 0.05

in the effectiveness of each intervention. On the RDQ, measuring functional limitations, the percentage of participants to improve did not differ immediately following any intervention, but by 26-week follow-up, differences emerged, favouring the active interventions, with the gains made in the MBSR group still significant at 52-week follow-up, but not those in the CBT intervention. However, at no time were there significant differences between outcomes in the active interventions. A similar pattern of results was found on the measures of pain bothersomeness. On the measure of change in pain intensity, the effects of the active interventions were more immediate, with gains relative to the usual care evident immediately after treatment and throughout the follow-up period. Again, no significant differences were found at any time between the two active interventions.

On the measures of mood, there were few consistent differences between the groups. MBSR participants improved more than those receiving usual care only on the depression and SF-12 Mental Component measures at 8 weeks. The cognitive behavioural intervention proved a little more effective, with participants randomised to CBT improving more than those receiving MBSR on the measure of depression at 8 weeks and anxiety at 26 weeks, and more than the usual care group at 8 and 26 weeks.

### Discussion

The authors conclude ‘there were no meaningful differences in outcomes between MBSR and CBT’, with both achieving significant reductions on pain measures, in particular, at a statistically ‘moderate’ (effect size) level. These data are perhaps consistent with increasing numbers of studies showing equality of effectiveness between a range of interventions designed to improve mood and function. These findings have led some to argue that the specific characteristics of any intervention may be equally or less important than non-specific factors such as increasing confidence in the ability to change, providing strategies of change, even if they differ in their specifics.

## Pain management clinics

So far, we have considered treatments for pain in isolation, without considering who provides the treatment or where patients may go for treatment. Nowadays, many hospitals provide services specifically for people with chronic pain – of whatever origin. These services will involve a number of people. Doctors, usually anaesthetists, provide expertise in the pharmacological and even surgical treatment of pain. Physiotherapists work with patients to develop exercise programmes that they can realistically expect to be able to engage in. Occupational therapists may work with patients to consider how they can improve their day-to-day activities around the home if their mobility is restricted. Specialist nurses may work with patients to develop pain management plans for individuals or groups of individuals. Psychologists may also contribute to and develop such programmes. Table 16.1 shows the outline of a typical outpatient pain management programme – conducted at the Gloucester Royal Hospital in the UK.

**Table 16.1** Outline of a typical pain management programme, in this case run at the Gloucester Royal Hospital in the UK

| | |
|---|---|
| **WEEK 1** | Welcome and introductions<br>Pain management philosophy<br>What is chronic pain? – questions answered<br>Introduction to exercise – sitting and standing<br>Pacing everyday activities<br>The stress response and introduction to diaphragmatic breathing |
| **WEEK 2** | Recap pacing<br>Goal setting and action plans<br>Introduction to exercise – lying<br>Sitting and chairs<br>Introduction to stretch and relax<br>Video patients doing exercises for comparison at end of group |
| **WEEK 3** | How pain works: the gate control theory of pain<br>How pain works: pain pathways<br>Thoughts and feelings about pain<br>Exercises<br>Stretch and relax<br>Action plans |

*(continued)*

**Table 16.1** *Continued*

| | |
|---|---|
| **WEEK 4** | Recommended use of medication for chronic pain<br>Communication and relationships<br>Pain management graduate perspective talk<br>Exercises<br>Introduction to relaxing your mind<br>Action plans |
| **WEEK 5** | Lifting and bending<br>Managing everyday activities<br>Sexual relationships<br>The benefits of exercise<br>Exercise<br>Relaxing your mind<br>Action plans |
| **WEEK 6** | Introduction to fitness and fitness equipment<br>Doctor's talk: medication, treatments and surgery for chronic pain, sleeping and beds/positions to ease pain<br>Action plans<br>Relaxation |
| **WEEK 7** | Flare-ups and setbacks<br>Helpful sleep habits<br>Video exercises and compare with the beginning of the course<br>Introduction to brief relaxation techniques<br>Reviewing progress, and setting goals for the follow-up sessions |

## SUMMARY

Pain is a widely prevalent phenomenon. Over 20 per cent of the general population are experiencing chronic pain at any one time, and the personal and social consequences of chronic pain are significant. Various types of pain have been identified:

- acute: lasting up to between three and six months;
- chronic: lasting more than three to six months; can be further categorised as chronic benign and chronic progressive pain.

Pain can also be defined in terms of its nature: its type, severity and pattern.

The experience of pain is moderated by a variety of physical and psychological factors, including:

- the degree of attention paid to the pain;
- the mood of the individual;
- the person's beliefs about the nature of the pain, including its cause and controllability.

Early specificity and pattern theories that did not take account of these psychological factors proved to be unsuccessful in explaining the various ways in which pain can be experienced. A more complex model developed by Melzack and Wall, known as the gate theory of pain, has superseded these models of pain. This suggests that pain is the outcome of a number of complementary or competing processes.

Any model of pain has to take into account how psychological factors affect the perception of pain. The gate theory of pain suggests that:

- Afferent nerves carry pain messages up to the substantiagelatinosa and then through the spinal gate mechanism to the brain.
- At the same time, psychological processes influence the activity of nerves leading from the brain to the spinal gate.
- Activation of both systems results in a variety of chemicals being produced within the gate (substantia gelatinosa), some of which 'open' the pain gate, some of which 'close' it. The main chemicals involved in reducing pain sensations in the substantia gelatinosa are endorphins.

Melzack has developed a more complex neurological model of pain, known as the neuromatrix, which accounts for phenomena previously difficult to account for by the gate theory (including phantom limb pain).

TENS is a physiological intervention based on the gate control theory of pain. Reliable evidence of its effectiveness is lacking.

Biofeedback interventions can help to reduce pain, but their overall effectiveness is often no greater than more general relaxation procedures. They may be best used when there are individual muscle groups contributing to the pain that are not relaxed following more general relaxation instructions, or for the treatment of headaches.

Both behavioural and cognitive-behavioural interventions have proved to be effective in the treatment of both acute and more chronic pain – but less then perhaps initially thought. Cognitive changes appear to mediate changes in the experience of pain. Mindfulness has also been shown to reduce pain, and (possibly to an even greater extent) quality of life and acceptance measures. Psychological interventions may be combined (at least in some cases) with antidepressant medication to provide maximal benefit.

## Further reading

Jensen M.P. and Turk D.C. (2014). Contributions of psychology to the understanding and treatment of people with chronic pain: why it matters to ALL psychologists. *American Psychologist,* 69: 105–18.

An interesting take on the wider impact of pain research and interventions.

Melzack, R. and Wall, P.D. (2016). *The Challenge of Pain*. London: Penguin.

A classic. The most up-to-date text by the originators of the gate control theory – and nearly £200 cheaper than the more recent *Wall and Melzack's Textbook of Pain*. Written in a non-technical way for the interested 'lay' reader.

Turk, D.C. and Gatchel, R.J. (2018). Psychological approaches to pain management: a practitioner's handbook. New York: Guilford Press.

Good practitioner based book on the mechanics of pain management.

Williams, A., Eccleston, C. and Morley, S. (2012). Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database of Systematic Reviews*, 11:CD007407.

Critical review of the pain management literature by leading UK pain academics.

Crombez, G., Eccleston, C., De Vlieger, P. et al. (2008). Is it better to have controlled and lost than never to have controlled at all? An experimental investigation of control over pain. *Pain*, 137: 631–9.

An interesting experimental study of what happens when you first provide control over pain, and then take it away.

Three differing theoretical psychosocial perspectives on pain:

Van Dammme, S., Legrain, V., Vogt, J. et al. (2010). Keeping pain in mind: a motivational account of attention to pain. *Neuroscience and Biobehavioral Reviews*, 34: 204–13.

Eccleston, C. and Crombez, G. (1999). Pain demands attention: a cognitive-affective model of the interruptive function of pain. *Psychological Bulletin*, 125: 356–66.

Meredith, P., Ownsworth, T. and Strong, J. (2008). A review of the evidence linking adult attachment theory and chronic pain: presenting a conceptual model. *Clinical Psychology Review*, 28: 407 – 29.

Klinger, R., Stuhlreyer, J., Schwartz, M., Schmitz, J. and Colloca, L. (2018). Clinical use of placebo efects in patients with pain disorders. *International Review of Neurobiology*, 139: 107–128.

Finally, a text examining the role and importance of the use of the placebo effect in real people with real pain.

WEB

Visit the website at **go.pearson.com/uk/he/resources** for additional resources to help you with your study.

# Chapter 17

# Improving health and quality of life

## Learning outcomes

By the end of this chapter, you should have an understanding of a number of psychological interventions that aim to:

- reduce distress: focusing on information provision, stress management training and providing social support
- improve disease management: focusing on information provision, self-management training, stress management training, facilitating family and social support, and the use of written emotional expression
- reduce the risk of future disease or disease progression: focusing on counselling, stress management and providing social support

# Every hospital should have one . . . a psychology department, that is

Probably not a headline you will actually read. But it should be. Most general hospitals in most countries, even where there are well-established professions of clinical and health psychology do not have access to psychologists. Read the research papers from countries such as the USA or UK, and you would believe that all hospitals are teaming with psychologists engaging in the interventions the empirical data show to be highly effective. But they are not. So why, if we know that psychology can ‘make a difference’, are so few hospitals actually employing professional psychologists? Perhaps physicians or surgeons do not think psychology has much, or anything, to offer? Well, many do. When one of the authors (PB) was working as a clinical psychologist in a general hospital, a number of physicians working in specialties including diabetes, gastroenterology, and renal medicine asked for psychological input into their clinics. They were very keen . . . until they were asked to pay for the service of a psychologist from their budget! At which point, they were much less keen . . . and eventually most decided not to have the psychologist. So, psychology is seen as important, but not central to the provision of quality care. Therefore, when developing interventions, psychologists need to consider not only what is effective but also what is cost-effective. Healthcare providers increasingly have to consider the bottom line: how much does it cost? Too much, and they will not pay. Something to consider as you read the chapter . . .

## Chapter outline

**This chapter focuses on a number of psychological interventions used to help people to cope with and manage serious illnesses. These interventions have a number of goals. Some seek to reduce the distress associated with having a serious illness. Others aim to help people to manage their illness as effectively as possible and to minimise its impact on their daily life. Yet others are designed to prevent the progression of an illness and minimise the risk of further health problems in the future. This chapter considers a number of interventions designed to achieve these goals in the context of chronic diseases, such as cancer, diabetes, coronary heart disease and arthritis.**

## Coping with chronic illness

The onset of a serious illness has many implications for both the individual concerned and those around them (see Chapter 12 ☛). Following the onset of symptoms, the person with the illness may experience the anxiety of waiting for and being given a serious diagnosis, the possibility of having to come into hospital, with its associated discomfort and disruption of normal life. In the longer term, they may have to come to terms with restrictions or handicaps associated with their condition and the possibility of a gradual decline in health. They may have to learn how to manage their condition or take action to prevent their health deteriorating further. Having a chronic illness presents the individual with a number of 'tasks'. People with arthritis, for example, may benefit from engaging in a variety of exercises to maintain joint mobility, and so on. Other diseases, such as coronary heart disease (CHD), may or may not be apparent on a day-by-day basis. However, changing risk factors such as diet or smoking may help to prevent the disease progressing further. A third issue that patients often have to deal with is the significant emotional distress that may accompany a diagnosis of severe or chronic disease.

The interventions considered in this chapter aim to help people to cope with each of these challenges. It examines the effectiveness of a number of approaches used to help people to reduce any distress they experience, to manage their disease, and to prevent it developing further. The therapeutic approaches we consider include:

- providing relevant information;
- stress management training (see Chapter 13 ☛);
- the use of social support;
- positive psychology approaches
- self-management training;
- enhancing social support;
- the use of **written emotional expression**.

Each type of intervention may have multiple benefits. Improvements in mood, for example, may increase the likelihood of cardiac patients participating in an **exercise programme**, and therefore impact on both their wellbeing and physical health. Conversely, taking part in an exercise programme may reduce depression or anxiety as the individual feels they are gaining control over their illness and their life. Stress management training may simultaneously reduce the distress associated with having heart disease

**written emotional expression**

a writing technique in which participants write about upsetting incidents either in their past or related to specific issues

**exercise programme**

a key element of most cardiac rehabilitation, including a progressive increase in exercise usually starting in a gym, sometimes developing into exercise in the home and beyond and improve its prognosis through its positive impact on cardiac function (Linden, Phillips and Leclerc, 2007). So, separating the specific outcomes of the various interventions is a little artificial. Nevertheless, we try to tease out each of these multiple end points and consider how well each intervention achieves each of these separate goals.

# Reducing distress

## Information provision

Many people with serious illness experience significant levels of distress. They may have concerns about their prognosis and treatment, the potential effects of their illness on their quality of life, and so on. Levels of distress are perhaps highest in the early stages of an illness or at times when the nature of an illness changes. We discuss these issues in more detail in Chapter 12 ☛. However, as examples of the level of distress many patients experience, about a third of patients with cancer and a quarter of those who have had a myocardial infarction (MI) report clinically significant levels of distress at some time in the course of their illness (e.g. Lane et al., 2002b). This can be reduced by various types of information, including information about:

- the nature of a disease and/or its treatment;
- how to cope with disease and/or its treatment;
- how to change behaviour in order to reduce risk of disease or disease progression.

Perhaps the simplest form of information provision involves keeping patients informed about the progress of their condition and its treatment. Uncertainty can increase distress – providing information, even simple information, can reduce it. Wells et al. (1995), for example, found that giving information to people with cancer about their upcoming chemotherapy was highly effective in reducing their levels of distress. However, this is not always found. Both Aranda et al. (2012) and Schofield et al. (2008) found fewer concerns over chemotherapy and related increases in self-efficacy following information-based interventions among all patients receiving chemotherapy, but no reductions in anxiety per se. However, improvements in anxiety may be found if an intervention specifically targets people with high levels of anxiety (Deshler et al., 2006). New technologies may also be used to help the provision of information. Lo et al. (2010), for example, found a computer-based learning education programme given to Taiwanese patients who had experienced significant burns resulted in significant benefits on measures of knowledge, use of pressure garments and anxiety.

More complex information-based interventions may also be relevant at the beginning of a serious illness. One particular issue that needs to be dealt with particularly sensitively is telling patients and relatives when they have a disease with a poor or fatal prognosis – a process often known as ‘breaking bad news’ (see also Chapter 10 ☛). The way that this information is given at this time may have important implications for how people cope and come to terms with their prognosis. Clearly, the communication skills of the person giving the bad news are important in the success of this process. Gebhardt et al. (2017), for example, found that patients, unsurprisingly, preferred communication that indicated their physicians’ clinical competence, was patient-centred, and asked about their information preferences (see also Chapter 10 ☛).

One simple informational strategy may further facilitate this process. A simple reminder of information given in consultation through provision of a recording of the consultation has proven of consistent benefit. Stephens et al. (2008), for example, found that patients given a recording of the consultation in which they were given a diagnosis of cancer were more likely to retain information about their condition and its treatment than those not receiving the intervention. The tape had no impact on mood. By contrast, Cope et al. (2003) compared the effectiveness of a variety of communication strategies with women having a scan for a potential foetal abnormality. Two weeks after their consultation, women who received an audiotape or letter summarising the information given in the session reported less anxiety than the control group without this information. The groups did not differ on recall of information.

Educational programmes whose primary intention is to help people manage a disease or reduce risk of further disease may also impact on mood. Hartford et al. (2002), for example, used a telephone contact programme for patients who had had a coronary artery bypass graft and their partners. The programme provided information on a number of issues to aid recovery, including a graded activity and exercise plan, as well as strategies to help cope with pain, and dealing with psychosocial problems, diet and medication use. The programme began with a meeting between a specialist nurse and the patient and their partner on the day of discharge, when they were provided with information about medication for pain, distances to walk, rest stops on the way home, the nurse's 24-hour telephone number, and a time when they would phone again. This was followed by six telephone calls at increasing intervals over the next seven weeks, during which problems were assessed and relevant information provided. Despite its emphasis on changing behaviour, it also proved effective in reducing both patient and partner levels of anxiety.

Why providing information about managing a disease can improve mood is not clear. Such interventions may provide patients with a sense of control over their illness and reduce uncertainties about their long-term health. They may also encourage participants not to overly restrict their lives as a result of their disease. Each may result in improved mood.

## Cognitive-behavioural interventions

Interventions based on cognitive behavioural principles involve teaching individuals directly how to cope with stress or improve their mood, using strategies including problem solving, cognitive restructuring: relaxation and mindfulness (as considered in Chapter 13 ☛).

Given the substantial evidence that such interventions can reduce clinical levels of anxiety and depression in a wide variety of mental health settings (see Bennett, 2021), it would be surprising if they did not have a similar effect in patients with physical health problems. And this is, indeed, the case. Even relatively simple interventions involving teaching relaxation techniques alone or in combination with other cognitive approaches have proven effective in reducing distress and (when measured) proximal physiological markers of stress such as cortisol (see Van Dixhoorn and White, 2005). These benefits are typically greater than would be expected following standard treatments. O'Neil et al. (2014), for example, found that 12 months following a combined cognitive behavioural intervention for depression and behavioural risk reduction programme delivered by telephone, cardiac patients who were depressed immediately following their infarction were significantly less likely to remain depressed and to have a better quality of life than those in a standard treatment control condition.

A second cardiac group for whom cognitive behavioural interventions have proven beneficial are people who have received an Implantable Cardioverter Defibrillator (ICD). These are small instruments placed in a patient's chest with leads leading to the heart. They monitor the heart for potentially fatal changes in heart rhythm, which they correct firstly by 'pacing' the heart and, if necessary, shocking it. Pacing involves increasing the heart rate for a short time. The shock is similar to that from an external defibrillator. Patients may not notice the pacing, although many do. They certainly notice the shock, which has been described as similar to being punched hard in the chest. Although most patients never actually experience a shock, they are all aware that it can occur. As a consequence, many avoid situations that they think may lead to an arrhythmia, such as engaging in exercise or potentially stressful situations. Those that have experienced a shock may develop a classically conditioned fear in situations where this has occurred or those similar to them. As a consequence, patients who both have and have not receive a shock may benefit from some sort of stress management programme. In one study of this approach, Sears et al. (2007) compared two active stress management interventions following ICD implantation, one lasting a full day: the other involving six, weekly, sessions. Both interventions were associated with short-term reductions in anxiety and cortisol levels.

### Mindfulness

Mindfulness is often used to help patients manage any stress they are experiencing; and it is proving an effective and easy to learn skill. In a summary of the relevant research to date, Greeson and Chin (2019) concluded that mindfulness-based interventions are likely to result in patients coping better with their symptoms, as well as improved overall wellbeing and quality of life. Examples of this type of intervention include a study by Henderson et al. (2013), who examined the effectiveness of a mindfulness-based intervention on women in early-stage breast cancer receiving radiotherapy. It proved beneficial on a range of measures including meaningfulness, helplessness, cognitive avoidance, depression, paranoid ideation, hostility, anxiety, global severity, anxious preoccupation, and emotional control. Similarly, Gross et al. (2010) compared the effectiveness of mindfulness with an education and no-treatment control conditions in patients who were sleeping poorly following organ transplantation. Following initial gains at two-month follow-up, by one year following the intervention, those in the mindfulness group continued to report less anxiety and sleep problems than those in either of the other groups. Finally, Ellis et al. (2019) found a mindfulness intervention in a group of young adults with poorly controlled type 1 diabetes reduced self-reported stress but had no effect on any clinical outcomes. By contrast, peer support groups focusing on both practical and emotional support impacted both on levels of depression and control over their diabetes.

## Positive psychology approaches

The interventions considered so far are based on attempts at the amelioration of distress, with distress being the key word. A very different approach involves adopting a more ‘salutogenic’ or ‘positive psychology’ approach. That is, enhancing and utilising positive aspects of an individual’s psyche to facilitate their wellbeing (Seligman and Csikszentmihalyi, 2000) rather than reduce their distress through the amelioration of stress-inducing factors including environmental and cognitive processes. An example of this approach can be found in a study by Jaser et al. (2019) who developed a ‘positive psychology intervention’ for young people with type 1 diabetes (see Chapter 8 (☛). Their intervention combined an education-based intervention and a relatively simple text-based positive psychology intervention. This involved participants being interviewed by a therapist during which they identified sources of gratitude (something that makes you happy even for a moment) and self-affirmation (something you are proud of). Over the next eight weeks, they received weekly texts asking them to report things that had made them happy or were self- affirming. In addition, they were asked to think of something that made them proud when they were struggling to test their blood sugar. Finally, parents were instructed to provide weekly affirmations. Compared to an education only intervention, this group evidenced significantly improved quality of life and less use of avoidance coping strategies (but no changes in glycaemic control) three months following the intervention. Unfortunately, the results were relatively short-lived, and there were no between group differences at six-month follow-up.

A similar approach was adopted by Huffman et al. (2019) in adult cardiac patients, following a myocardial infarction. The intervention comprised twelve, weekly, phone calls with the study ‘interventionist’. During these phone calls participants were encouraged to engage in a range of positive psychology exercises, including:

- *Gratitude for positive events*: recall three events in previous week that led to satisfaction, happiness or other positive state.
- *Gratitude letter*: write a letter thanking person for act of kindness.
- *Capitalising on positive events*: recall three recent positive events, then share with others or otherwise recall/celebrate.
- *Using personal strengths*: choose a personal strength and use this in a new way over the following week.
- *Enjoyable and meaningful activities*: complete activities that bring immediate improvement in mood and/or that are deeply meaningful.
- *Perform act of kindness*: complete three acts of kindness in one day, then write how they made participant feel.

The impact of this intervention was compared to a similarly timed educational intervention. Participants completed an average of ten of the twelve interviews, indicating high acceptability of the intervention. It also proved superior on measures of mood (positive affect, anxiety, depression) immediately at the end of the intervention and three months later.

A particularly simple positive psychology intervention which has been used as an adjunct to cognitive behavioural therapy involves a process known as **benefit finding**. This involves exploration of beneficial consequences from what may usually be seen as a negative event, such as developing cancer or being infected with HIV. Benefits identified include:

- a greater enthusiasm to live life to the full;
- making positive life choices as a result of illness;
- a greater appreciation of being alive;
- improved relationships with partner.

This approach has proven effective in reducing distress. Stagl et al. (2014), for example, found that women who received stress management training including benefit finding following surgery for breast cancer experienced fewer depressive symptoms than those in a control group up to five years following the intervention. Similar gains have been made among men following medical treatment of prostate cancer (Penedo et al., 2006) and men and women during a course of radiotherapy (Krischer

**benefit finding**

a process of finding beneficial outcomes as a consequence of what is normally seen as a negative event, such as developing cancer or being infected with HIV et al., 2007). An interesting study, not just for its findings, but for its statistical analysis, was reported by Zhu et al. (2018), who examined different trajectories of change following a benefit-finding based intervention in cancer patients. Following the intervention, they identified five benefit finding 'trajectories': (i) what they termed, 'high level-stable' (i.e. high levels of pre-existing benefit finding – no change; 8 per cent of recipients), (ii) 'very low level-small increase' (16 per cent), (iii) 'low level – small increase' (39 per cent), (iv) 'low level – large increase' (9 per cent), and (v) 'moderate level – stable' (28 per cent). Not surprisingly, perhaps, those in the low-level high increase group reported the greatest improvements on a measure of depression. Benefit finding was not related to anxiety.

## Enhancing social support

We discussed in Chapter 12 ☛ how social support can improve or maintain both mental and physical health. With this in mind, a number of studies have evaluated the impact of support groups designed to provide social support from people experiencing similar health problems. Many of these have been led by professionals and include an element of group therapy or working towards group goals.

Giese-Davis et al. (2002) reported that women with advanced cancer who participated in social support groups reported less suppression of negative moods while also showing less aggressive, inconsiderate, impulsive and irresponsible behaviour in comparison with the no-treatment group. They concluded that this form of intervention can help women to become more expressive of their emotions without becoming more hostile. Supportive interventions such as this appear to be of benefit to women across a variety of cultures, including Iranian (Montazeri et al., 2001) and Japanese (Fukui et al., 2000) women. By contrast, men may be relatively unwilling to attend support groups, but may still benefit from peer support. Weber et al. (2007), for example, found men who had experienced a **radical prostatectomy** benefited on measures of depression and self-efficacy following meeting a fellow patient once a week for eight weeks to discuss any concerns they had and coping strategies they could use.

**radical prostatectomy**
otherwise known as a total prostatectomy, this involves using surgery to remove all of the prostate as a cure for prostate cancer

**Photo 17.1** Social support can help you keep healthy. Sometimes by just having someone to talk to. Sometimes by supporting healthy behaviours – even in difficult circumstances!

*Source*: Michal Bednarek/123rf.

With increasing access to the internet, the need for face-to-face support is changing, and some innovative work is now beginning to measure the benefits associated with online support groups. In one study of this approach, Vilhauer et al. (2010) found that 73 per cent of women with metastatic breast cancer invited to participate in a virtual group did so, and most continued to remain part of the group over a period of two months, accessing it on average six days a week. Although they did not measure mood, another study of this approach by the same group reported that the women reported benefits including group cohesiveness, information exchange, feelings of being in the same situation as others, hope, catharsis, and altruism. Similarly, Bond et al. (2010) reported a study targeted at older adults with diabetes, involving web-based social support that could involve a range of web-based contacts including 'synchronous chat sessions with peers and a nurse' as well as contact through email and bulletin boards and information pages. This resulted in significant gains on measures of depression, quality of life and self-efficacy in comparison to usual care. Adopting a similar approach, Stinson et al. (2016), in their iPeer2Peer programme, matched trained young mentors with similar aged peers (see discussion of similar approaches in Chapter 7 ☛) to help them cope with Juvenile Idiopathic Arthritis. Contact was made via skype and involved a series of planned 'meetings' between peer and patient. Their research primarily evaluated the acceptability of the programme; and it was indeed acceptable, with 85 per cent of planned contacts achieved, and each contact being quite extensive. Next, they need to show this was also effective in changing mood.

Before leaving this issue, it is important to note that although socially based interventions have proven effective, at times they may be less effective than other, individually based interventions, such as mindfulness (Carlson et al., 2013). In addition, Pollock et al. (2007) found that many patients preferred to turn to friends and families for support and did not wish to attend more professionally organised support groups. This cautionary note supports an approach in which family and partner skills are strengthened, and provide the support given to the patient. This approach does appear of benefit. Li and Loke (2014), for example, summarised the then available data and concluded that working with couples in which one person was diagnosed with cancer improved the quality of life, sexual functioning, and marital satisfaction of both patients and partners, as well reducing levels of distress. In a subsequent study, Nicolaisen et al. (2018) evaluated the impact of an attachment-theory based intervention involving people early in their treatment for cancer. Its goals and strategies including:

- increasing couples' sense of attachment-related security by focusing on their relationship strengths and attachment security and supporting them in 'creating new emotional experiences';
- identifying individual emotional distress and needs by supporting couples in in verbalising their level of emotional distress and emotional needs and feeling of attachment security;
- sharing knowledge about breast cancer, partners' previous experiences with cancer, and how they influenced their current situation;
- supporting disclosure of previous experiences of emotional distress, individual and consideration of how the couple can use these experiences to help in their current situation.

Interestingly, although this intervention improved dyadic adjustment more than a control condition involving usual care, this did not translate to gains on a measure of cancer-related distress; people in both conditions improved equally. As is often the case, the impact of the intervention was highly specific and related to its primary goal.

## WHAT DO YOU THINK?

The potential interventions aimed at people with physical health problems vary enormously in scale and nature. They can be simple single page self-help sheets to long term complex cognitive behavioural interventions. There is a general tendency, perhaps, to think that the more complex the intervention, the more benefit it is likely to be. But is this the case? Most of the people at whom these interventions are targeted have not sought out any form of psychological intervention, and may not be motivated to engage in complex, time- and energy-demanding interventions. So, it is possible that they will be too complex, too demanding, and shorter or simpler interventions may actually be more effective. So, think how you would feel if you went into hospital with, say, diabetes and were invited to take an eight-week stress management or similar course even if you don't feel particularly stressed. How would you feel about taking part? Would you prefer something of this depth, or would you struggle to take part. Would a shorter, less complex, intervention be more acceptable? Or would you feel neither is of benefit, as your problems are largely physical?

# Managing illness

A second set of interventions can be used to help people to gain the skills and motivation to manage the symptoms of an illness as effectively as possible: to maintain an exercise and mobility programme in rheumatoid arthritis, an insulin regimen in type 1 diabetes, and so on. The goal of the intervention here is not to prevent the development of a disease but to minimise its negative impact on the affected individual.

## Information provision

There is a significant body of evidence showing that patient education programmes can enhance knowledge about a condition or its management, at least in the short-term. However, even where increases in knowledge are achieved, they may not always impact on behaviour or symptom control. Indeed, a number of studies have found only a marginal relationship between educational programmes and behavioural change. In a systematic review of 11 such programmes for people with asthma, for example, Gibson et al. (2000) concluded that, while such programmes increased knowledge, there was no evidence that they impacted on measures of medication use, doctor visits, hospitalisation and lung function. However, the simple addition of an action plan (see discussion of problem-focused counselling and implementation intentions in Chapter 6 ☛) seems to enhance their effectiveness (Powell and Gibson, 2003).

The internet now provides a key source of information for many patients; some even provide questions and answers driven by artificial intelligence (Rose-Davies et al., 2019). That said, while the internet is now the most likely source of information for younger patients, older patients are still more likely to use print media or expert sources of information (Heiman et al., 2018), while in Saudi Arabia, the predominant sources of information remain physicians and the television (Jamal et al., 2015).

The internet provides both formal ‘official’ sites and ‘unofficial’ sites, many of which advocate the use of a variety of treatment approaches or condemn them as dangerous and unacceptable. Given the plethora of, often contradictory, information on the internet, access to this information can both benefit patients and carry the potential for confusion and even harm. It also presents significant challenges for doctors when giving information about a particular condition. Witness one anecdotal story in which a UK doctor prescribed tamoxifen, a drug treatment known to significantly reduce the risk of cancer recurrence in women who have had breast cancer. In the consultation, he described both the benefits and the common side-effects and health risks of taking the drug to one patient. With this knowledge, she decided to take the drug on a preventive basis. The next day she telephoned the doctor to say that she was no longer willing to take the drug as she had searched a number of US websites, and their descriptions of the health risks associated with the drug made her decide against its use. While in one way this may be seen as the power of truly informed consent, what had frightened this woman was reading a list of diseases that had occurred in women taking the drug. What she did not have was the data to contextualise this list, which included many conditions that may have occurred in only a very small percentage of those taking the drug or may not even have been the result of taking tamoxifen. Mindful of this, Kalichman et al. (2006) found that an eight-session training in the appropriate use of the internet given to people living with HIV/AIDS resulted in increased access to health information on the internet, and lower vulnerability to misinformation and fraud.

Another response to this issue has led healthcare providers to establish their own web-based information that patients can easily access and that can provide appropriate information. Typical of many professional web-based health information sites, the American Heart Association (www.americanheart.org) has substantial information related to heart failure and CHD, hypertension, high cholesterol and **atrial fibrillation**. Even more impressively, it has a web-based interactive tool through which patients can obtain a personalised report of ‘scientifically accurate’ treatment options, a list of questions to ask their doctor on their next visit (which has been shown to improve doctor–patient communication and patient satisfaction – see Chapter 10 ☛), and key information they need to participate in their treatment. The effectiveness

**atrial fibrillation**

a heart rhythm disorder (arrhythmia); it involves a very rapid heart rate, in which the atria (upper chambers of the heart) contract in a very rapid and disorganised manner and fail to pump blood effectively through the heart of this type of intervention is difficult to assess. However, people who access health- and illness-related websites are generally more knowledgeable than those who do not (Kalichman et al., 2003), although this may be the result of better-informed people being most likely to access internet sites relevant to their illness. Nevertheless, these data suggest that the internet may prove a useful resource for people with many chronic conditions, and as we shall show later, can prove an effective medium of change.

## Self-management training

Perhaps the best-known approach to helping patients to gain control over their illness is known as self-management training; an approach pioneered by a Californian nurse practitioner, Kate Lorig, (e.g. Lorig and Fries, 2006). Those who undertake this form of training are often referred to as 'expert patients'. The approach involves teaching affected individuals how to manage their illness in a way that maximises control over their symptoms and quality of life. It is based on social cognition theory (e.g. Bandura, 2001), which suggests that patients can learn self-management skills from practice and watching others, and that success in achieving control will lead, in turn, to increased confidence and continued application of new skills. Accordingly, the core of self-management training is a structured, progressive, skills-training programme that ensures success at each stage before progression to the next. Self-management programmes are usually, but not uniquely, run as group interventions, facilitating the process of learning from observation of others.

The approach is specifically targeted at the effective management of disease. It does not focus on the emotional sequelae of disease; nor is it intended to be a preventive intervention. Early self-management programmes focused on helping people cope with rheumatoid arthritis, typically addressing issues such as:

- exercising with arthritis;
- managing pain;
- eating healthily;
- preventing fatigue;
- protecting joints;
- taking arthritis medication;
- dealing with stress and depression;
- working with the doctor and healthcare team;
- evaluating alternative treatments;
- outsmarting arthritis: problem solving.

The original self-management programmes addressed all issues with all people. However, some issues may be more relevant than others depending on recipients' differing levels of knowledge, health-related behaviours, and so on. As a result, a number of programmes have now moved from a 'one size fits all' approach to tailored programmes that provide a range of modules that participants can select according to their particular needs (Iversen et al., 2010). Evers et al. (2002) evaluated the effectiveness of one such programme targeted at people with rheumatoid arthritis. Modules included those targeted at helping people to cope with fatigue, negative mood and pain, and to maintain or improve social relationships. Each module included both educational and homework elements. In addition, they outlined strategies such as cognitive restructuring of dysfunctional thoughts, problem solving, and goal setting in the context of illness. As examples, the pain module contained strategies including the identification of pain-provoking cues in daily life and attention diversion; the fatigue module contained strategies such as the identification of fatigue patterns, planning and structuring daily activities and relaxation. The programme resulted in mid- to long-term gains on a number of psychological measures, including the use of active coping strategies, mood, fatigue and helplessness in comparison with a no-treatment condition.

Following their success with arthritis, self-management programmes have widened their scope to help people to manage a number of long-term conditions. Franek (2013), for example, reported the findings of a systematic review of self-management programmes, based on Lorig's model, across a range of conditions including arthritis and chronic pain, chronic respiratory diseases, diabetes, heart disease, and stroke. When compared to usual care, the approach was associated with 'modest' improvements in pain, disability, fatigue, depression, health distress, self-rated health, and health-related quality of life. By contrast, the interventions did not reduce the number of visits to general practitioners or Emergency Medical Units nor the number of admissions to hospital and time spent in hospital. More cautiously, despite this type of programme becoming increasingly used in healthcare systems across many countries, and highly valued by its participants (Sharpe et al., 2017), a Cochrane review by Kroon et al. (2014) identified that much of the evidence on which the programmes were based was not strong, and that when compared with an attentional control (as opposed to usual care) the evidence of benefit was limited to either 'no or small benefits . . . but . . . unlikely to cause harm.'

Self-management programmes need not be delivered 'live'. There are now several examples of graduated skills-based programmes that have translated key elements of the self-management process into written or computer-based form. The *Heart Manual,* for example, followed the developmental approach of gradual change and skills learning suggested by Lorig. In the programme, a loose-leaf A4 size book (the Heart Manual) provides a six-week graduated programme of behavioural change, focusing on increasing exercise, use of stress management procedures, dietary and smoking change. During each week, patients are encouraged to plan and monitor their progress. Patients are contacted on three occasions by telephone to discuss adherence to the programme – but are not encouraged to use the telephone call as a counselling contact. The most recent evaluation of this approach was reported by Jolly et al. (2007). They randomly allocated participants who had experienced an MI from inner-city, ethnically diverse, socially deprived areas of the West Midlands of England to receive either a hospital-based cardiac rehabilitation programme or the Heart Manual used at home. Both involved programmes including exercise, relaxation, education and lifestyle counselling. Significant improvements in total cholesterol, smoking status, self-reported physical activity and diet were seen in both conditions between baseline and the six-month follow-up. In addition, no clinically or statistically significant differences were seen between the home- and centre-based groups, suggesting that the home intervention is a viable and effective intervention.

Self-management programmes can also be implemented simply and cheaply using the internet or interactive programmes on a range of platforms. Devi, Powell and Singh (2014), for example, found a six-week internet delivered cardiac rehabilitation programme providing information about the prevention of further heart problems, and establishing user goals in terms of physical activity, diet, managing emotions and smoking to be more effective than normal care in a group of patients diagnosed with angina. Those using the programme logged in on average three times per week and showed significant improvements relative to the normal care group on measures of daily steps walked, duration of 'sedentary activity', weight, emotion outcomes and frequency of angina. The health problem faced by participants in this study suggests older individuals are willing and able to engage in internet-based programmes. However, this may not always be the case. Several studies have shown younger people to enjoy and benefit from the use of such technology in managing illnesses such as diabetes (Jeon and Park, 2019) and asthma (e.g., van der Meer et al., 2007).

Older populations, or those without computer literacy, may not feel comfortable with such an approach. In an ethnically diverse Californian sample, Sarkar et al. (2007), for example, found that 69 per cent of their respondents reported interest in telephone support, 55 per cent wanted group medical visits, while only 42 per cent would use the internet. Unsurprisingly, people who reported themselves as having poor literacy were more likely to be interested in telephone support than the alternative approaches. Whatever their effectiveness, self-management programmes may be enhanced by remote processes. A number of studies have examined the benefits of remote patient-monitoring of physiological measures of disease, such as insulin levels and lung function for asthma in their own home. In these, patients take measures, which are relayed to clinicians and relevant laboratories who then provide online feedback. Although the direct one-to-one nature of this approach has proven difficult to conclusively prove effective (e.g. Hanlon et al., 2017), it forms a potentially important adjunct to a number of self-management interventions.

## Cognitive behavioural interventions

A number of interventions have focused on teaching stress management procedures in an effort to control the symptoms of disorders as diverse as rheumatoid arthritis and atopic dermatitis whose course and prognosis is thought to be affected by stress.

One such condition is known as irritable bowel syndrome (IBS: see Chapter 8 ☛), in which cognitive behavioural stress management interventions have achieved similar gains on symptom control to medical interventions when conducted face to face (Spiller et al., 2007) or through the use of self-help material augmented by brief telephone contact (Moss-Morris et al., 2010). Hypnosis has also proven effective. In a comparison between hypnosis and a dietary intervention, Peters et al. (2013), for example, found similar benefits on IBS symptoms and better psychological outcomes following hypnosis.

Taking the issue one step further, Kennedy et al. (2005) reported a study in which they examined whether stress management could add to the effectiveness of a drug that slows down the gut's activity and is generally used to treat IBS. All the people in the study were first given the drug treatment. Those who continued to have IBS symptoms six weeks later were either entered into a stress management programme or continued on their drug regimen in the hope that additional time on the drug would improve their symptoms. Patients in the cognitive-behavioural programme fared best, reporting significant improvements on a variety of measures of IBS symptoms as well as reductions in measures of emotional distress. Adopting a similar model, Dobbin et al. (2013) compared the effectiveness of a brief (one or two session) hypnotherapy or biofeedback interventions in patients in whom medical treatment had proven ineffective, and found both to improve symptomatology, and to be equally effective.

Episodes of angina may be triggered by emotional as well as by physical stresses (see Chapter 8 ☛). Accordingly, a number of studies have explored the potential benefits of stress management procedures in people with this condition. Summarising the data to date, Kisley et al. (2012) concluded that such cognitive behavioural interventions successfully reduce the frequency of angina for up to three months post-intervention, followed by a diminishing benefit at one-year follow-up assessments. From a different perspective, Moore et al. (2007) developed an intervention designed for people who became anxious about their angina symptoms and perhaps other non-angina-like sensations they interpreted as indicating an episode of angina or myocardial infarction (MI) (see Chapter 8 ☛). This involved: (i) using interviews to identify and modify any misconceptions about the nature of angina, (ii) teaching patients how to challenge and rationalise catastrophic thoughts when they experienced chest sensations that had previously led to them seeking medical help, and (iii) learning relaxation. The study was not a randomised trial, but comparisons were made with prior behaviour. In these, average hospital admissions per patient per year were reduced from an average of 4.2 admissions to 1.8. Of course, these changes may simply reflect naturally occurring changes over the course of the illness, but they also hint at possible reductions in the cost of care for these individuals as well as improved quality of life of the individuals involved.

## Case history: Mr P

Mr P provides an interesting case involving the use of stress management and angina. His problems began when he was admitted to hospital following an MI. As with most patients, he spent two days in the coronary care unit before being transferred to a medical ward, and was discharged a few days later following an uneventful time on that ward. Unfortunately, when he went home, he developed the symptoms of angina, which on occasion mimicked the symptoms Mr P had experienced at the time of his initial infarction: chest pain, shortness of breath and feeling dizzy. One of these episodes occurred following a major sale (he was a sales representative) led him to feel very excited, after which he walked out of a building into a freezing cold night to go to his car to drive home. The combination of adrenalin-fuelled excitement and sudden exposure to cold air triggered a significant episode of angina. Unfortunately, he found these symptoms extremely frightening and interpreted them as indicating he was having a further MI. This resulted in him hyperventilating, exacerbating his physical symptoms, having a 'full-blown' panic attack, and then calling out an ambulance to be admitted to the same hospital. As on the first occasion, he was discharged from hospital the following day after being told that he had 'only' had an episode of angina.

In an attempt to stop this happening again, he was referred to a clinical psychologist. The challenges of therapy were to help Mr P distinguish (and then control) any panic symptoms from those of his heart disease, and to be able to distinguish any symptoms of angina from symptoms of a true MI. A mistake at any stage in this process could prove, literally, fatal. The intervention proved relatively simple, as Mr P was keen to adopt a psychological approach to managing his problems. The first stage involved working out exactly what was contributing to his feelings of panic. The key issue here was panicky thoughts, in particular thoughts that his heart disease was out of control and that he could die unless he got medical help. This led to increased sympathetic arousal, ironically placing more strain on his heart and increasing his angina, and hyperventilation which added to his feelings of being out of control, and dizziness.

The goal of therapy was to break this circle. This initially involved Mr P learning to relax and to use some simple breathing techniques he could use to slow his breathing when he became anxious. He practised these skills regularly until they became relatively easy to implement. Then, working with the psychologist, he developed a strategy to use if he experienced any angina symptoms. These were:

- Assume that the symptoms were angina, not a heart attack. Use positive self-talk to remind himself that he had experienced the symptoms before and they were not a sign of impending death, that he could control them, and if he used his gtn [glyceryl trinitrate] spray (see Chapter 8 ☛) they would soon go.
- Use relaxation and breathing exercises to bring his symptoms under control.
- Wait 5–10 minutes, to see whether the symptoms reduced as a result of these procedures.
- If they did not, to call an ambulance and seek medical help.

He talked this action plan through during a therapy session and planned on its use at key times during the day. He used it twice, successfully, in the month following its development. In the next month, he did not experience any panic attacks, and was discharged from the psychology services. Another successful case!

The potential benefits of stress management for the control of diabetes are perhaps less obvious than those related to angina. Nevertheless, there are reasons to presume that they could form an effective element in any programme of diabetes control. Stress often precedes periods of reduced adherence to self-care behaviour and may be associated with inappropriate changes in eating patterns (Snoek and Hogenelst, 2008). In addition, high levels of stress hormones such as cortisol reduce the body's sensitivity to insulin and may be accompanied by elevations in blood sugar (Surwit and Schneider, 1993). Accordingly, there is a reasonable case to suggest that interventions targeted at mood may also influence diabetic outcomes; and this indeed seems to be the case. Attari et al. (2006), for example, reported an Iranian study comparing the effectiveness of stress management versus no intervention in the long-term control of high blood sugar levels in people with type 1 diabetes. Their main outcome measure was a substance known as HbA(1c), which indicates levels of blood sugar over the previous three months. Over the course of the three-month intervention, participants in the stress management group had lower levels of HbA(1c) than those in the no-intervention group.

Similar gains have also been reported in people with type 2 diabetes (see Chapter 8 ☛: Surwit et al., 2002). Interestingly, Surwit and colleagues found that those people who reported the most stress did not benefit any more than those with lower levels of stress; perhaps because they found the stress management intervention more difficult to implement. Despite these positive outcomes, however, some caution should be applied. Li et al.'s (2014) meta-analysis of ten trials of cognitive behavioural treatment of depression in diabetic patients found, unsurprisingly, consistent improvements on measures of depression and quality of life. They also found some evidence of lower blood sugar on a one-off measure (fasting blood sugar), but no overall evidence of improved control over sugar levels over the longer term.

Perhaps the best interventions are those that combine teaching stress management techniques with other strategies to help to control diabetes. Grey et al. (2000), for example, compared an intensive diabetes management programme combined with a stress management programme with the diabetes management programme alone in young people with diabetes. By one-year follow-up, participants in the combined intervention had lower blood sugar levels and a higher belief in their ability to control diabetes and general health than those in the single condition. In addition, participants in the combined intervention were less likely to gain weight than those in the diabetes management programme, and women in this condition were least likely to report **hypoglycaemic episodes**. A similar combined intervention was reported by Safren et al. (2014) for people with uncontrolled type 2 diabetes, targeting both depression and adherence to medication. Gains were made on both levels of adherence and depression in the short-term (three-month follow-up), and the gains on adherence continued undiminished up to the year follow-up assessment. Less positively, gains on depression diminished over this time. Nevertheless, the potential health impact of increased medication adherence in this group is likely to be significant and this is an important gain.

## Enhancing social and family support

Just as family and wider social groups may be the target of interventions designed to enhance emotional outcomes, they can also be used to facilitate good self-care among people with chronic conditions. Greco et al. (2001), for example, reported outcomes of an intervention in which young people with diabetes and their best friends took part in a group intervention aimed at increasing diabetes-related knowledge in both participants and increasing the friend's support of the patient's diabetes care behaviour. The intervention achieved these goals. In addition, the young people's wider groups of friends understood more about diabetes, and parents reported less diabetes-related conflict.

With the development of modern technology, support from peers or fellow patients need not always be live. The internet has become an important means of keeping in touch, although the results of Lindsay et al. (2009) indicated that if the goal is behavioural change, this is more likely to be achieved if an internet support group 'meeting' is moderated by a health professional or other informed individual. They evaluated the degree of risk behaviour change in cardiac patients living in an economically deprived area of the UK who were able to access

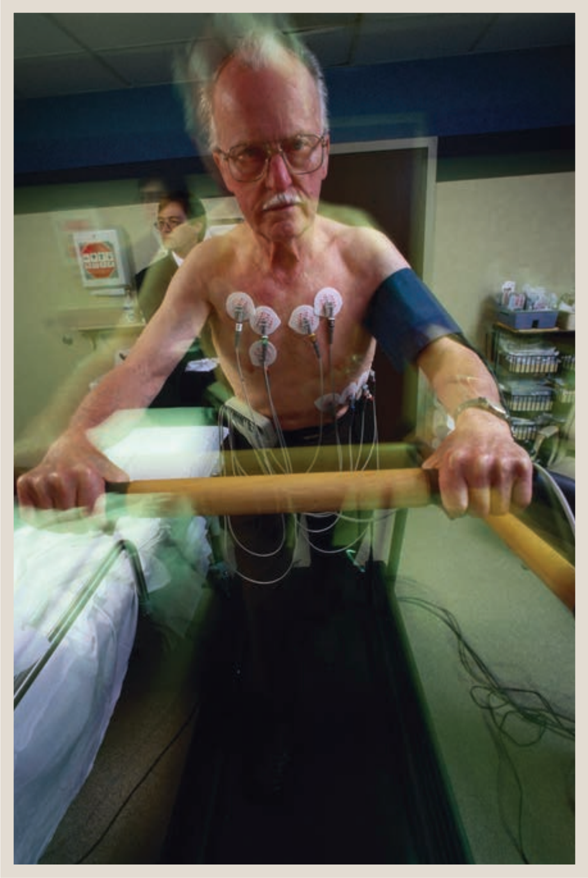


**Photo 17.2** The treadmill can provide a good test of cardiac fitness while in the safety of a medical setting

*Source*: Alvis Upitis/Stockbyte/Getty Images.

hypoglycaemic episode
occurs when the body's glucose level is too low; frequently occurs when too much insulin or oral diabetic medication is taken, not enough food is eaten, or following exercise without appropriate food intake – symptoms include excessive sweating, paleness, fainting and eventually loss of consciousness

professionally moderated then un-moderated online support groups. During the moderated phase, the group members achieved more changes in diet than a usual care control group. However, during the following un-moderated phase, they not only lost the behavioural gains they had made, but they also made *more* appointments with healthcare staff than those in the control condition. Why this would happen is unclear, but the potential for an un-moderated group to spread worry and concern among its members rather than ameliorate is clear.

Involving partners in any intervention may also be of value: and may be done quite simply. Taylor et al. (1985), for example, compared the effects of wives' differing levels of involvement in an assessment of their husband's exercise capacity following an MI. The wives were allocated to one of three conditions: (i) no observation of the test, (ii) observing their partners taking part in a **treadmill test** to assess their cardiac fitness, (iii) observing their partners take the test and also taking part in it themselves. The key measure in the study was the wives' ratings of their partners' physical and cardiac efficiency. As may be predicted, the confidence the wives had in their husbands' exercise capacity increased across each level of engagement in the exercise testing process. In a more complex intervention, Garcia-Huidobro et al. (2011) found working with families to be more effective than individual care in the treatment of uncontrolled type 2 diabetes in adults living with at least one family member. However, involving partners in educational programmes may not always be successful. Riemsma et al. (2003) reported that when both patients and their partners attended a cardiac group education programme, participants reported *decreases* in self-efficacy and increased fatigue. By contrast, patients participating in group education without partners showed *increases* in self-efficacy and decreased fatigue; perhaps because they had to take personal control and responsibility for their own care.

Given the necessary involvement of family in the care of younger people with chronic illnesses, it should be no surprise that a number of interventions have targeted families or parents in attempts to help manage these conditions. Interestingly, these have often focused on the wider family dynamics as much as facilitating control over the identified child's condition. Yeh et al. (2016), for example, worked to empower family caregiver's ability to manage their child's asthma problems through working through family discord, developing family problem-solving and working to get a 'joined-up approach' to facilitating the asthma treatment regime of their target child. The intervention was successful at a systemic level, improving family functioning on measures including cohesion and conflict resolution, as well as improving lung function and reducing the frequency of coughing and wheezing when compared to a usual care group. Using a similar systemic approach, Morawska et al. (2016) used the Triple P parenting approach (the Positive Parenting Programme), which involved two, two-hour, meetings with parents fostering a behavioural approach to working with their child to help them manage their treatment for asthma and eczema. As a consequence, compared to a usual care condition, parents reported greater control and confidence in controlling their child's eczema, reduced symptom severity, and better quality of life for the family, but not for the affected child.

## Emotional expression

Perhaps the most unusual therapeutic approach now being used with people who have physical health problems is the variously termed narrative or written emotional expression. The work stems from the findings by Pennebaker in the 1980s (see Pennebaker et al., 1990) of the psychological effects of a writing task in which healthy participants, usually students, wrote about an event or issue from the past that had caused them upset or distress in a way that explored their emotional reaction to that event for about 15–20 minutes on three consecutive days. Typical instructions for this exercise were:

1. Find a place where you will not be disturbed. You can write by hand or on a computer – whatever you are most comfortable with. If you don't want to write, you can also talk into a tape recorder.
2. Plan on your writing for a minimum of three days and a minimum of 15 minutes a day. The only rule is that

**treadmill test**
a test of cardiovascular fitness in which participants gradually increase the level of exercise on a treadmill while having their heart monitored with an electrocardiogram

you write continuously. If you run out of things to say, simply repeat what you have already written.

3. Instructions: really let go and write about your very deepest thoughts and feelings about *X*. How does *X* relate to other parts of your life? For example, how do they tie into issues associated with your childhood, your relationship with your family and friends, and the life you have now. How might they be related to your future, your past, or who you are now? Why are you feeling the way you are and what other issues are being brought up by this?
4. You can write about the same general topic every day or a different one each day. Don't worry about spelling or grammar. Your writing is for you and you alone. Many people throw away their writing samples as soon as they are finished. Others keep them and even edit them.
5. Be your own experimenter. Try writing in different ways. If you find that you are getting too upset in your writing, then back off and change directions. Your goal here is to better understand your thoughts and feelings associated with *X*. See which approach to writing works best for you.

Following this process, participants typically reported short-term increases in depression or distress, but in the mid- to long-term experienced better mood and, importantly in this context, seemed to have better physical health as measured by immune function and the frequency of visiting a doctor (see Esterling et al., 1999). It took some time for this approach to be tested in patient populations. However, the interventions that have been conducted appear to show benefits. Smyth et al. (1999), for example, compared the effects of written expressed emotion and a neutral writing task in patients with rheumatoid arthritis (RA) and asthma. Those in the intervention condition were asked to write about the 'most stressful experience they had ever undergone'; those in the control group were asked to write about time-management issues as an exercise to reduce stress. Both types of patient in the intervention group fared better than their equivalents in the control group at four-month follow-up: patients with asthma showed improvements in lung function, while patients with RA showed improvements on a combined index measuring physician-rated factors such as disease activity, joint swelling and tenderness, and the presence and severity of joint deformities as well as patient reports of any constraints on daily living tasks. Accordingly, the gains reported cannot simply be attributed to changes in self-report of symptoms as a function of improved mood following the intervention: they appear to be 'objective' gains in disease activity.

In a further examination of the role of emotional disclosure in RA reported by Lumley et al. (2011), gains were also made on variables including speed of walking, pain, swollen joints and physician-rated disease activity six months following a written emotional expression intervention. Warner et al. (2006) also reported similar benefits for young people with asthma, and began to explore which elements of the writing task appeared to mediate the improvements they found. By analysing the content of participants' writing, they found that the greatest improvements in asthma were associated with improved insight into the issue the participants were writing about, and the expression of more negative emotions.

In a study evaluating both effectiveness of the written emotional expression approach and attempting to determine who benefits most from it, Stanton et al. (2002b) assigned participants, all of whom were in the early stages of breast cancer, to write about either: (a) their deepest thoughts and feelings regarding breast cancer (the emotional expression condition), (b) positive thoughts and feelings regarding breast cancer (the positive emotional expression condition), or (c) facts about their experience of having breast cancer (the neutral task). Once again, the emotional expression seemed to be of benefit. In comparison with the neutral task, participants in the emotional expression condition reported fewer somatic symptoms and fewer visits to the doctor with worries about cancer or related medical conditions. Of interest was that women who typically used active coping strategies appeared to benefit most from the emotional expression condition. The positive emotional expression task appeared to benefit those women who were typically avoidant, presumably because it did not force them to confront their fears and other issues raised by their disease.

Despite these positive results, it should be acknowledged that not all interventions involving written expression are effective. Harris et al. (2005), for example, found it did not benefit adults with asthma. Similarly, there may be some contexts in which the expression of emotions is actually counter-productive. Panagopoulou et al. (2006) found that women who were emotionally expressive were less likely to become pregnant while undergoing in vitro fertilisation than those who contained their emotions. Subsequently, Renzi et al. (2019) found improvements in pregnancy rates, while Frederiksen et al. (2017) found no difference between those who did and did not engage in expressive writing. They did, however, find that expressive writing related to participants' emotional response to their infertility unsurprisingly increased their levels of distress; perhaps giving an explanation for Panagopoulos's negative findings.

# Preventing disease progression

## Psychosocial interventions

Three conditions in in which the impact of interventions to reduce mortality, or factors associated with mortality include cardiac conditions and cancer; the two leading causes of premature death in the industrialised world.

The impact of traditional cardiac rehabilitation programmes incorporating some form of cognitive behavioural intervention has been explored in a number of studies. In a Cochrane review involving a wide range of psychological intervention approaches, Richards et al. (2017) utilised data from 35 studies involving nearly 11,000 participants. These combined data showed that psychological interventions appeared effective in reducing stress and depression, particularly among those individuals with clinical levels of each disorder, and achieved a 21 per cent reduction in deaths from cardiac disorders, but no reduction of risk for recurrent non-fatal MI.

In an early exploration of the impact on cognitive behaviour therapy on cardiac mortality and morbidity, the Recurrent Coronary Prevention Program (Friedman et al., 1986) targeted men following an MI who high on a measure of Type A behaviour (see Chapter 12 ☛). Participants were allocated to one of three groups: standard cardiac rehabilitation, cardiac rehabilitation plus Type A management, and a usual care control. The standard rehabilitation programme involved small group meetings over a period of four-and-half years, in which participants received information on medication, exercise and diet, as well as social support from the group. The Type A management group focused on a sustained programme involving training in relaxation, cognitive techniques, and specific behavioural change plans to reduce their Type A behaviour. Over the four-and-a-half years of the intervention, those in the Type A programme were at half the risk of further infarction than those in the traditional rehabilitation programme, with total infarction rates over this time of 6 and 12 per cent in each group, respectively. This large-scale study has been replicated in a number of smaller studies (e.g. Gulliksson et al., 2011) and remains one of the most convincing studies of the effectiveness of stress management on survival following an MI. Of further note are the findings of Blumenthal et al. (e.g. 2005) who have found similar or lower levels of mortality following stress management programmes for cardiac patients than following traditional exercise-based programmes. Meditation may also prove an effective intervention for people with CHD. Castillo-Richmond et al. (2000), for example, found evidence of a slowing in the development (and even perhaps a modest decrease) in the thickness of atherosclerosis in the carotid artery of hypertensive African Americans who were taught meditation compared to controls who were not.

Depression substantially increases risk of infarction or re-infarction; and reductions in depression are associated with reduced risk for recurrent MI (e.g., Smolderen et al., 2017). With this in mind, the ENRICHD study (Berkman et al., 2003) targeted nearly two and a half thousand depressed cardiac patients in an attempt to reduce their risk of further infarction. All participants in their active intervention arm received two or three treatment components, each aimed at improving their emotional state over a period of up to one year: (i) group cognitive-behavioural therapy; (ii) social support enhanced by training participants in the social skills needed to develop their social support network; and (iii) antidepressant medication for people who did not evidence any improvement in mood received. A comparison group received the usual care provided by the institutions in which the study took place. Unfortunately, the results of the study were disappointing. Although the ENRICHD intervention did result in marginally lower levels of depression than those achieved in the usual care condition, there were no differences in survival between the two groups over the two years following infarction. Unfortunately, the sheer size of the study meant that the investigators had limited control over the interventions received by patients in both arms of the study. This meant that the usual care received by some people in the control condition was, in fact, very similar to that provided by the ENRICHD study. In addition, attendance at the ENRICHD intervention was less than optimal, with most patients attending about eleven sessions: not that different to many of the control group interventions. Perhaps because of these factors, the differences in levels of depression between the two groups, although statistically significant, were of modest clinical value. Accordingly, it remains possible that the reductions in depression in the ENRICHD condition relative to the control condition were not sufficiently large to bring about reductions in risk for further MI.

Survival following cancer and a range of other disorders is likely to mediated, at least in part, by the strength of the immune system. With this in mind, Black and Slavich (2016) identified 20 randomised controlled trials that had evaluated the impact of psychological interventions on various immune parameters in people with rheumatoid arthritis, ulcerative colitis and breast cancer, positive to HIV, as well as 'at risk' populations such as caregivers of people with Alzheimer's disease. A number of studies have focused on the levels of circulating cytokines (see Chapter 8 ☛), which are essential for protection against a range of systemic challenges, but when dysregulated and chronically elevated increase risk for disease, poor healing, and mortality. Accordingly, the research here is somewhat complex, with some studies intending to increase levels of cytokines, while others aim to reduce chronically high levels.

Overall, changes in immune function were significant and in a beneficial direction, although frequently modest, and not always sustained over time. Bower et al. (2015), for example, aimed to reduce levels of pro-inflammatory cytokine activity in women diagnosed with early-stage breast cancer. Participants in the active intervention took part in a six-week mindfulness course. The intervention proved successful, with evidence of reduced inflammatory activity in the mindfulness condition relative to a control, waiting list, condition. However, the effects were no longer found at three-month follow-up and were not dependent on the amount of time spent practicing mindfulness.

Of those studies that measured T lymphocyte levels (see Chapter 8 ☛), the majority showed increased counts of T cells relative to control conditions in people with HIV and breast cancer following mindfulness interventions, implying an improved prognosis following the use of mindfulness, although levels of NK cells did not differ in a study of the impact of mindfulness reported by Lengacher et al. (2013). There does appear to be consistent evidence of at least short-term changes in immunological function following psychological interventions. The question that therefore needs to be addressed is whether these changes are sufficient to impact on health and survival. Here, the evidence is mixed.

## IN THE SPOTLIGHT

Reading the report of the ENRICHD study, which was published in the prestigious *Journal of the American Medical Association*, it is clear that the readers of this journal had one interest. Did treating depression save lives? This is a question that has excited many health psychologists as well as medical doctors – and it is very important. But because it did not save lives, many psychologists consider the ENRICHD study to be a failure. But was it? Yes, from a biomedical stance, the results of the ENRICHD study were disappointing. But what about a more psychological perspective?

Depression is a potentially disabling condition that has significant implications for the quality of life and rehabilitation outcomes of both patients and the people involved with them. While psychologists should be involved in the questions of the impact of disease on physiological processes, they should also be careful not to lose sight of other psychological questions and adopting too strong a biomedical stance in the questions they address. Changes in depression are an important outcome in themselves – not just a vehicle to reduce mortality. From this perspective, the ENRICHD intervention proved a costly one that fared moderately better than the care usually provided. As such, it provides a wealth of information about how to identify and treat depression in cardiac patients, with potentially significant benefits to future patients. We should be careful not to throw out the 'psychological baby' when we throw out the 'medical bath water'.

In one trial involving women with advanced cancer, Spiegel et al. (2007) failed to replicate their earlier findings (Spiegel et al., 1981) of overall survival benefit following an intervention involving weekly supportive meetings during which participants were encouraged to express their concerns and distress and be supported in doing so. However, one sub-group of patients, whose condition did not respond to hormonal treatment, did benefit from the intervention. Among them, the length of survival in those who received the intervention was 30 months, compared to 9 months in the non-intervention group. It is possible that the highly effective medical treatment wiped out any benefits of the psychological intervention in women who were more responsive to treatment. Similarly, Stagl et al. (2015) reported the long-term outcomes (between 8- and 15-years post-diagnosis) of a cognitive behavioural stress management intervention provided to women following surgery for their breast cancer. This large study of over 350 women provided either a ten-week group CBT programme or one-day psychoeducational seminar control. By follow-up, the overall data suggested a non-statistically significant trend for more women who received the CBT programme to be alive than those in the control condition, and less likely to have experienced a recurrence. A more restrictive analysis, focusing on women who had experienced invasive cancer indicated even stronger effects, with highly statistically significant gains on both measures.

Overall, then, the outcomes of these studies are mixed. Indeed, the findings of a review by Mirosevic et al. (2019) suggested the answer to the question whether psychological interventions can prolong life is both yes and no, as studies on survival have shown mixed outcomes. They identified 12 trials comparing the effects of psychosocial interventions with usual care on survival. Overall, the evidence indicated modest gains in length of survival following such interventions (the authors describe this as small to moderate), with significant benefits in survival achieved by ten of the twelve studies. They authors also noted that much of this benefit was found in patients who received the intervention relatively early in their disease course, before it had significantly progressed, and who were over the age of 50 at the time of its occurrence. Those who received cognitive behaviour therapy early following their cancer diagnosis were over twice as likely to have longer survival rates than those who receive therapy later.

## RESEARCH FOCUS

### Does mindfulness do more than make people feel better?

Witek Janusek, L., Tell, D. and Mathews, H.L. (2019). Mindfulness based stress reduction provides psychological benefit and restores immune function of women newly diagnosed with breast cancer: a randomized trial with active control. *Brain, Behavior, and Immunity*, 80, 358–373.

Women with breast cancer typically have elevated stress levels, particularly in the period following diagnosis. This stress can result in immune system dysregulation, and in particular reduced Natural Killer Cell Activity (NKCA) and altered levels of cytokines (see Chapter 8 ☛), both of which may compromise the body's natural control over the cancer. The present study was intended to identify whether reductions in stress following training in mindfulness meditation could improve immune function in a cohort of women diagnosed and treated for breast cancer but unselected for their levels of distress.

### Method

#### *Participants*

Participants were women aged between 28 and 75 years, newly diagnosed with breast cancer. Exclusion criteria were previous experience of mindfulness, recurrent cancer, immune-based disease and mental health problems.

#### *Conditions*

Women were recruited in clinics and were assigned to each condition prior to recruitment (to prevent bias in allocation to condition). They were randomly assigned using computer generated randomisation in age 'blocks': 28–45, 45–59, 60–74 years to one of the following:

- *Mindfulness-based Stress Reduction (MBSR):* an eight-week programme following the Kabat-Zinn model of mindfulness training (see Chapter 13 ☛), with a six-hour mindfulness retreat on the fifth week. The sessions were in group format and led by a clinical psychologist certified as an instructor in the Kabat-Zinn method.
- *Active control condition:* an 8-week educational programme mirroring the mindfulness programme in terms of contact with health professionals, and addressing issues including understanding breast cancer, communicating with healthcare providers, bone health, and image and cancer.

### *Measures*

Measures were taken on five occasions: T1, two weeks following surgery; T2, four weeks into the programme; T3, completion of programme; T4 one month follow-up; and T5, six months follow-up. Participants completed psychometric measures and gave blood at each time to measure:

- *Perceived Stress Scale*: a measure of overall global stress.
- *Centre for Epidemiologic Studies, Depression Scale*: a frequently used measure of depression.
- *Multidimensional Fatigue Scale Inventory – short form*: including overall fatigue and fatigue experienced in five domains (general, emotional, physical, mental, vigour)
- *Pittsburgh Sleep Quality Inventory*: seven subscales: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. A total score of 5 or greater indicates 'poor' sleep.
- *Five Facet Mindfulness Questionnaire*: addresses five facets of mindfulness – acting with awareness, non-judging of inner experience, and non-reactivity to inner experience.
- *Natural Killer Cell Lytic Activity*: Lytic activity, which involves the destruction of cells infected by viruses or tumours, was taken to be the number of NK cells required to achieve 20 per cent lysis (destruction) of target tumour cells in a standardised test of exposure to such cells. That is, it is a measure of the 'effectiveness' of the NK cells to destroy cancerous cells, expressed as a 'percentage toxicity'.
- Cytokine levels in the blood plasma, and the level of cytokine production were measured under controlled conditions.

## Results

The final sample comprised 164 women (84 in the mindfulness condition) with an average age of 55.1 years. Most (86.8 per cent) were in stage 0 or stage 1 of the cancer (see Chapter 8 ☛), with only a minority being more progressed. All had had surgery, with the majority (76 per cent) having breast conservation and 24 per cent having mastectomy. There were no significant group differences on any measure at baseline.

Key findings from the study were:

### *Psychological measures*

Compared to the control condition, women in the MBSR condition experienced significantly steeper linear change (e.g., quicker improvements) on measures of perceived stress ($p < .01$), fatigue ($p < .001$), sleep disturbance ($p < .05$). A non-significant trend towards a more rapid reduction in depression measures ($p$ .08) was also reported. This led to between condition significant differences in the level of perceived stress at T4 ($p = .004$) and T5 ($p = .016$) and sleep disturbance at T4 ($p = .045$)

### *Immune outcomes*

Change on immune measures were also linked to condition.

Women in the education control condition had significantly more rapid ($p < .001$) increases in the pro-inflammatory cytokine, interleukin (IL) 6 as well as TNF (tumour necrosis factor) alpha ($p < .05$) levels.

Women in the MBSR condition experienced significantly more rapid ($p < .001$) increases in NKCA cells and interferon (IFN) gamma ($p < .001$).

Following the intervention (T4), the between group differences were significant on all measures, with women in the MBSR condition having significantly lower

*(continued)*

**Table 1** Changes over time on key psychological and immune variables.

| | T1 | | T3 | | T4 | | T5 | |
|---|---|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | Mean | SD | Mean | SD |
| CESD | | | | | | | | |
| MBSR | 13.67 | 11.26 | 10.46 | 10.40 | 10.31 | 10.15 | 10.57 | 9.50 |
| ACC | 13.84 | 9.21 | 11.42 | 8.80 | 11.79 | 10.89 | 10.69 | 10.38 |
| PSS | | | | | | | | |
| MBSR | 17.85 | 8.51 | 13.66 | 6.79 | 13.76 | 7.59 | 13.70 | 7.10 |
| ACC | 17.81 | 6.82 | 15.66 | 6.87 | 16.67 | 8.27 | 16.09 | 7.76 |
| MFSI | | | | | | | | |
| MBSR | 16.21 | 22.08 | 9.65 | 23.54 | 7.72 | 20.91 | 8.28 | 22.46 |
| ACC | 14.41 | 18.12 | 10.09 | 19.98 | 11.29 | 22.55 | 10.33 | 25.58 |
| PSQI | | | | | | | | |
| MBSR | 8.24 | 3.43 | 6.48 | 3.12 | 6.55 | 3.13 | 6.94 | 3.26 |
| ACC | 7.81 | 3.84 | 7.36 | 3.55 | 7.31 | 3.82 | 6.88 | 3.58 |
| NKCA (LU at 20%) | | | | | | | | |
| MBSR | 73.33 | 44.46 | 80.20 | 58.93 | 89.92 | 49.77 | 103.38 | 44.18 |
| ACC | 78.05 | 52.44 | 65.26 | 30.26 | 63.88 | 39.33 | 77.88 | 50.76 |
| IL-6 (pg/ml) | | | | | | | | |
| MBSR | 1.81 | 1.61 | 1.43 | 0.91 | 1.45 | 0.97 | 1.28 | 0.78 |
| ACC | 1.85 | 1.50 | 1.68 | 1.05 | 1.43 | 0.85 | 1.39 | 1.02 |
| TNF alpha (pg/ml) | | | | | | | | |
| MBSR | 1.64 | 0.96 | 1.50 | 0.78 | 1.66 | 0.82 | 1.60 | 0.83 |
| ACC | 1.63 | 0.91 | 1.85 | 1.11 | 2.16 | 1.43 | 1.91 | 1.25 |

levels of IL-6 ($p = .001$) and TNF alpha ($p = .05$) and higher levels of IFN gamma ($p = .001$) and NKCA cells ($p = .001$) (see Table 1). These differences continued up to T5.

Despite these between group differences, while significant associations were found between levels of mindfulness and measures of perceived stress, depressive symptoms and fatigue at each of the assessment time points, no significant associations were found between mindfulness (with p values ranging from 0.57–0.93) and immune outcomes or between the psychological measures and immune parameters (p values range, 0.29–0.73).

## Discussion

Overall, the data are positive, in that taking part in the mindfulness intervention was associated with a more rapid restoration of NKCA and IFN-gamma (which promote an immune response to the cancer) and an attenuation in proinflammatory cytokines (IL-6 and TNF alpha) which have been associated with poorer prognosis and cancer progression. The increase in NK cells is important as they are known to eliminate residual tumour cells not affected by treatment, prevent relapse, and increase survival. As noted in the main chapter, we know that early psychological intervention in cancer is associated with the best outcomes in terms of cancer progression and mortality, and this finding provides a mechanism through which such gains may be achieved.

The lack of direct association between psychological measures and immune function was disappointing, but not unique to this study. Similar findings were found, for example, in a study evaluating how a stress-based intervention affected the immune response to the flu vaccine involving one of the book authors (Vedhara et al., 2003). As reported in the present study, the intervention had a positive impact on the immune response, but no association was found between measures of stress and immune function. It may be that such measures are inherently 'noisy' and lack the molarity to consistently reveal associations between psychological and measures such as immune function.

## SUMMARY

The chapter considered psychological interventions designed to achieve three interacting goals in patients with serious chronic diseases:

- to reduce distress;
- to improve disease management;
- to reduce risk of future disease or disease progression.

A number of approaches have been successfully used in each case.

Reductions in distress have been achieved by the use of:

- appropriate information (including information about a condition or coping strategies to minimise distress or improve control over the condition);
- stress management training while waiting for a diagnosis, during treatment and while coping with the emotional stress of living with a long-term illness;
- providing social support – often in the guise of professionally run support groups.

Improvements in the management of illness have been achieved by:

- providing information – particularly information that provides a structure to achieve symptom control rather than simply providing information about a condition or its treatment;
- training in self-management programmes, with emphasis shifting from the provision of general 'one size fits all' programmes to more bespoke programmes specifically developed to suit participants' needs;
- stress management training in conditions in which stress is involved in their aetiology (e.g. IBS) or may exacerbate symptoms (e.g. angina, diabetes);
- improving social and family support;
- written emotional expression.

Finally, a number of interventions may impact on longer-term health:

- Stress management appears to be of benefit in improving health in a number of conditions, including CHD and HIV/AIDS.
- Treatment of depression in cardiac patients may impact on prognosis, although the ENRICHD study suggests that this approach should be viewed with caution.
- Social support may be of benefit, although the promise of some early studies has not been repeated in later studies.
- There appears to be some long-term benefit in terms of survival in cancer patients following psychological interventions, although this may be limited to sub-groups of patients within the larger population.

Overall, there is significant evidence that psychological interventions can be of great value in helping people to come to terms with the emotional consequences of having a serious chronic illness. They may also be of benefit in aiding day-to-day symptoms and even longer-term prognoses in a more limited set of conditions.

## Further reading

Shields, G.S., Spahr, C.M. and Slavich, G.M. (2020). Psychosocial interventions and immune system function: a systematic review and meta-analysis of randomized clinical trials. *JAMA Psychiatry*, 77: 1031–1043.

Recent, and positive, review of outcomes following primarily stress management interventions. Needs a bit of psychoneuroimmunology knowledge, but worth the read.

Winkley, K., Upsher, R., Stahl, D. et al. (2020). Psychological interventions to improve glycemic control in adults with type 2 diabetes: a systematic review and meta-analysis. *BMJ Open: Diabetes Research and Care*, 8: e001150.

A detailed, and somewhat pessimistic, review of the impact of behavioural interventions in one, very important, disease.

Bradt, J., Dileo, C. and Potvin, N. (2013). Music for stress and anxiety reduction in coronary heart disease patients.

*Cochrane Database of Systematic Reviews*, Dec 28;12:CD006577.

A reminder that there are many ways to reduce stress and improve health in people with chronic disease.

Rogers, M. A., Lemmen, K., Kramer, R. et al. (2017). Internet-delivered health interventions that work: systematic review of meta-analyses and evaluation of website availability. *Journal of Medical Internet Research*, 19: e90.

Interesting review considering the effectiveness of the internet as a means of intervention.

Lenferink, A., Brusse-Keizer, M., van der Valk, P.D. et al. (2017). Self-management interventions including action plans for exacerbations versus usual care in patients with chronic obstructive pulmonary disease. *The Cochrane Database of Systematic Reviews,* 8: CD011682.

As it says on the tin, a review of self-management and action plans to manage pulmonary disease.

Visit the website at **go.pearson.com/uk/he/resources** for additional resources to help you with your study.

# Part IV

# From theory to practice

# Chapter 18

# From theory to practice

## Learning outcomes

By the end of this chapter, you should have an understanding of:

- the need for theory-led practice
- how psychologists may influence practice, and some of the barriers to the effective development of practice
- the training and role of health psychologists in differing parts of the world
- influences on the uptake (or not) of recommended treatment approaches

## Health psychology is the future

The most prevalent diseases, certainly across industrialised nations, are now frequently a consequence of how we behave: our lifestyle. Indeed, the World Bank considers the impact of one disease alone, type 2 diabetes, will have profound effects on the economy and cost of the provision of healthcare. The treatment of these lifestyle diseases often involves adherence to long-term medication and/or changes in lifestyle to manage symptoms or mitigate risk of increasing health problems. So, behaviour frequently causes diseases and behavioural change is central to their treatment. But this is not the limit of the role or impact of health psychology in healthcare. As we have seen in this book, psychology is relevant to a wider range of issues within healthcare, including medical decision making, communication between health professionals and their patients, the organisation of health services and occupational stress, and so on.

So, the future is exciting for health psychology. Or is it? Health psychologists have yet to obtain a strong professional presence in many healthcare systems. The need for psychological skills, so easily recognised by health psychologists, is not necessarily recognised by others. Many health professionals feel they already have the relevant skills and there is no need for potentially expensive specialists. So, arguments for and against a role for health psychologists within a number of healthcare systems are still being aired. And their conclusion remains in doubt. It is crucial that those involved in health psychology now spread the word and demonstrate their expertise to make it clear that we have a unique set of skills and abilities that healthcare systems cannot afford to ignore . . .

## Chapter outline

**This chapter draws together a number of the strands of research and the practice of health psychology. It starts with a reminder of the need for health psychologists not only to develop the practice of health psychology, but also to develop and utilise theory in our practice of health psychology. It provides some examples of how theory may inform practice, before examining who may come to actually use interventions based on health psychology theory. The chapter considers some of the barriers to the dissemination of good healthcare practice, whether based on health psychology or input from other disciplines. It also considers the development of health psychology as a healthcare profession across a number of healthcare settings.**

# The need for theory-driven practice

In this section we consider how health psychology theory can be applied in healthcare settings. This book has outlined a wide range of contemporary evidence showing the importance of psychological and psychosocial factors in explaining health, health-related behaviour, and the outcomes of interventions to affect both. Key variables that influence behaviour have been integrated into coherent theories such as the theory of planned behaviour, social cognitive theory, and so on. More complex models, such as the health action process, have further integrated these theories into second-order theories of behavioural acquisition and change. These theories are developing and expanding as a direct result of the theoretical work conducted by many academic health psychologists: the theory of planned behaviour is now, for example, often considered in the context of additional variables such as moral norms and anticipated regret (see Chapter 5 ☛). However, such theories are not only of academic benefit to researchers and other psychologists but are also of importance to a range of healthcare practitioners, because they help identify which, out of the vast range of potential factors, are most likely to influence behaviour. They can help us construct interventions that are most likely to be effective in a variety of contexts. That is not to say that atheoretical interventions may not work; we have shown that many do. Rather, it means that theoretically led interventions have a better chance of addressing key factors that influence health-related behaviours than those that are not so guided.

An example of this can be found in work on smoking cessation. Ask many health professionals how to help someone stop smoking, and they will probably say that the best way is to scare them into behavioural change. Empirical evidence suggests that such an approach will work for some, but not the majority of smokers. Psychological theory, which is now clearly integrated within the COM-B approach (see Chapters 6 and 7 ☛) provides a series of alternative factors that may be more influential:

- The *health belief model* suggests that not only do we need to convince smokers that smoking will result in serious illness and that they are at significant risk of developing such illnesses, but we also have to convince them that the benefits of stopping smoking (health, cost, fitness, etc.) outweigh the benefits of continued smoking (avoidance of withdrawal symptoms, loss of social camaraderie, 'It can't happen to me', etc.).
- The *theory of planned behaviour* further emphasises the role of attitudes and beliefs in behaviour change. It also indicates the potential role of peers and other important others in developing personal strategies in stopping smoking. It, and the *health action process*, also clearly indicate the benefit of planning behavioural change, not simply acting on impulse.

- *Social cognition theory* suggests that before people are motivated to stop smoking and/or to continue in any efforts to remain smoke-free they have to believe they have the ability to do so. The principle of vicarious learning suggests we gain both skills and self-efficacy from observation of coping models – and these should form an integral part of smoking cessation programmes. The theory also suggests that although health may be a long-term gain following smoking cessation, we are largely influenced by shorter-term benefits. Accordingly, smoking cessation programmes should highlight the short-term benefits of stopping smoking as well as the long-term health gains.
- *Theories of addiction* as well as empirical data provide insight into the need to avoid gradual withdrawal of addictive substances such as cigarettes, but to cut down to the point of reaching the level of smoking immediately above the onset of withdrawal symptoms, and then to go ‘cold turkey’.

Finally, the emphasis of many theories on the role of environmental triggers to behaviours such as smoking indicates the benefit of modifying the environment in the early days of smoking cessation to either minimise the number of cues to smoking a person may experience or plan specific strategies on how to deal with any urges to smoke as a consequence of such cues should they occur. These factors have not designed an intervention programme, but they provide a good framework, based on first principles, on which to base any smoking cessation programme.

We now consider how two theories may inform our understanding of an individual’s response to a set of symptoms and how they can determine the types of intervention we conduct. Some of the first theoretically driven interventions involved changing patients’ inappropriate responses to their illness; and in particular the pain they were experiencing (see also Chapter 16 ☛). Seminal work by Fordyce (1982) was influenced by learning theory and used operant conditioning techniques to influence patients’ pain-related behaviour. Fordyce argued that our response to pain is determined by both internal sensations of pain and the environmental contingencies any pain-related behaviour provokes. He noted that some individuals responded to pain with either an exaggerated response (groans of pain, winces, and so on) or an absence of behaviour (avoidance of behaviours that may result in pain). Both of these responses may result in poor outcomes. Exaggerated responses may result in over-medication, as carers and health professionals respond to these pain behaviours; avoidance behaviours may result in a reduction in physical capacity. Fordyce argued that rather than treat the pain, which we cannot see and evaluate, we should instead manage the pain-related behaviours by either administering pain relief on a regular basis, ignoring (not reinforcing) pain behaviours, and/or rewarding (reinforcing) appropriate behaviours such as engagement in physical activity. He showed in a series of elegant case reports how these simple interventions could significantly alter quite marked inappropriate use of pain medication.

More recent influences on the practice of healthcare practitioners have been based on cognitive models of how we respond to and cope with serious illnesses. Leventhal’s self-regulation theory (see Chapter 9 ☛), for example, suggests we generate a set of beliefs, or more technically, we appraise the nature of our symptoms in terms of the nature of the illness, its consequences, curability and so on. As in broader theories of emotion, this appraisal determines our emotional reaction to the illness. Although Leventhal does not specify specific appraisal–emotion links, other more general theories of emotion (e.g., Lazarus, 1999) make these links for us. Appraisals of an illness as serious and out of our control may be associated with the emotions of anxiety and depression. Appraisals of an illness as serious but controllable may be associated with some anxiety, but also optimism and hope. Appraisals also determine our behavioural response to the illness. Appraisals that an illness is long-term and untreatable, for example, may result in different behaviours to appraisals that the illness will quickly go and is easily treatable. Self-regulation theory also suggests that coping is elicited by our emotional response to a situation, and in particular a negative emotional response. The coping strategies we adopt, whether emotion- or problem-focused, are designed to moderate these negative emotions. Accordingly, someone who has had a myocardial infarction may choose to exercise or stop smoking: behaviours that will both help reduce risk for disease progression and, by doing so, reduce their anxieties associated with such risk. Another individual may *avoid* exercise, as the sensations they experience while doing so remind them of their illness and the threat it carries to their health.

As we have seen in Chapter 11 ☛, where the coping responses match the reality of the situation, they are likely to be effective. Where there is a mismatch between appraisals and reality, inappropriate coping strategies may be evoked. Worse, inappropriate coping may lead to poor emotional and health states, and lead to a downward cycle of negative expectations and responses to illness. We need to know more about these various steps. However, the basic framework enables effective theoretically driven interventions. For example, we know that any intervention designed to optimise patients' responses to the onset of illness may benefit from a number of elements, including:

- Identification of illness beliefs and attempts to change them if they are either incomplete or incorrect: see for example, the work of Petrie et al. with cardiac patients described in Chapter 17 ☛. The intervention may also involve the use of cognitive restructuring techniques described in Chapter 13 ☛.
- Teaching skills to help people cope more effectively with the stress of living with a serious illness. Encourage the use of problem-focused coping as appropriate in order to facilitate active attempts to enhance control over the illness and emotion-focused coping strategies or skills such as mindfulness to provide ways of reducing any emotional distress the individual may experience.
- Behavioural hypothesis testing (see Chapter 13 ☛) to disconfirm any inappropriate beliefs an individual may hold.

Again, theory does not provide an individualised intervention, but it does provide a structure around which any intervention may be designed.

Another way of thinking about how we develop individual interventions can be drawn from the clinical psychology world. Here, interventions are driven by a formulation: an explanation of how and why the individual is experiencing the problems they are. Although the content of a formulation will necessarily differ according to the orientation of the therapist, a typical cognitive behavioural formulation would consider:

- The presenting problem(s): what is troubling the individual or impacting negatively on their health?
- Predisposing factors: what factors have left them vulnerable to any problems they are experiencing?
- Precipitating factors: why have they developed problems now?
- Perpetuating cognitions and consequences: what thoughts are they experiencing, and behaviours are they engaged in that are maintaining their problems?

Together, these lead to a formulation of the problem and a treatment plan that would be acceptable to the individual and within their resources to carry out.

The wider social and psychological environment may also be invaluable in facilitating and maintaining behavioural change. Such interventions draw on models of family dynamics, as we discuss in Chapter 15 ☛ and may involve a less individualised approach to behaviour change than is usually the case. These models may be particularly pertinent in the context of changing young people's behaviour (although we would argue that similar issues could usefully be considered in many interventions to adult behaviour). DiMatteo (2004a), for example, highlighted the following factors that should be considered when attempting to do so:

- building trust between health professional, young patient and parent through supportive and sensitive interactions and discussion of perspectives on treatment needs and goals;
- consideration of specific beliefs and attitudes about treatment needs and goals, including areas of discrepancy between young person and parent, and in particular identifying the young person's health beliefs;
- identification and discussion of norms and expectations in relation to the desired behaviour that the young person is exposed to: for example, parental adherence behaviour and treatment anxieties, cultural and social norms of treatment adherence;
- gaining and encouraging family commitment to treatment and within-family communication if problems with treatment arise by providing social support, possibly via illness-specific support groups;
- working together to overcome barriers and increase belief in the ability of the young person to make any required behavioural changes (self-efficacy);
- tailoring wherever possible the treatment regime to the lifestyles of the family unit.

After reading this text, you may think that the issues raised here are obvious, and surely must be taken into account when health professionals develop their interventions in the 'real world'. But this is far from the case in reality, and health psychology needs to continue

## IN THE SPOTLIGHT

How can we make intervention research more useful? One of the problems in many intervention trials is that neither the intervention nor the control condition are described in sufficient detail to allow them to be fully understood and replicated. From an intervention development perspective, this lack of precision has meant it can be difficult to identify the exact nature of any intervention, particularly one with several elements, and therefore to determine across studies which elements worked, and which did not. The lack of information in relation to the control condition also makes it difficult to identify what the participants did and did not receive, and therefore to judge the effectiveness of the intervention. Control conditions are often described as ‘usual care’, which it not very revealing. In the case of cardiac patients, it can mean anything from three monthly meetings with a consultant cardiologist to pre-existing cardiac rehabilitation programmes. In cancer, it can vary from meeting trained cancer specialists with time to spend exploring issues relevant to patients, or nothing at all. With this in mind, a number of UK researchers, including Susan Michie and Charles Abraham, have called for all studies to have more information about each element of the study, and for researchers to use a common vocabulary (called a behaviour change taxonomy in the case of behavioural change interventions) in describing them (Michie et al., 2013). This should facilitate the development of better interventions as we can better understand their exact nature, drilled down to their component parts, and begin to tease out what is more or less effective, and in what combinations.

*Source*: Michie, Richardson, Johnston. et al. (2013).

developing relevant theories and interventions based upon them, and in particular interventions that are ‘doable’ within the context of busy health professionals (we return to this issue later) as well as considering ways in which the implementation of these interventions can be encouraged. We turn to this issue in the next section.

# Getting evidence into practice

Having considered how psychological theory can guide the development of patient-focused and population-level preventive interventions, we now consider how health psychologists and others may facilitate the application of these interventions with relevant client groups. Nowadays, health professions of all types do not often have the luxury of trying out or using interventions that they ‘like’ or ‘feel’ may be effective, although in earlier chapters we have called for careful piloting of interventions where possible.

Increasingly, we are constrained by guidelines and limits of acceptable interventions (see the relevant discussion in Chapter 6 (☛). In the UK, for example, the National Institute of Health and Care Excellence (NICE) has developed guidelines for the treatment and pathways of care relating to a range of health conditions. These include both medical and psychological care. For example, they have established guidelines for the content of cardiac rehabilitation programmes and included psychosocial interventions within the wider care of conditions such as rheumatoid arthritis, diabetes and irritable bowel syndrome. They even have a set of guidelines identifying strategies of behaviour change in public health (NICE, 2007).

These, and other guidelines are based on what is known as evidence-based practice. To create them expert groups are formed to develop guidelines based on their clinical knowledge and the research indicating the most effective treatments available. Once established, these guidelines become a benchmark against which health services can judge the quality of their service and evaluate its standards against national guidance. This is the point at which research begins to inform practice, not just at an individual practitioner level, but at a national and international level. The downside of this process is that guidelines based on evidence are essentially conservative and can somewhat stifle innovation. It takes time for novel interventions to accrue sufficient evidence to justify their inclusion in the guidelines.

A second type of evidence is closer to the data and not dependent on expert groups' time and efforts can also make a significant contribution to practice. A number of organisations now provide excellent systematic reviews and meta-analyses of a range of intervention approaches in healthcare. Two of the best known are perhaps the Cochrane Collaboration (https://www.cochrane.org/), which is probably the most relevant to individual interventions in physical and mental health, and the Joanna Briggs Institute (https://joannabriggs.org/) that focuses more specifically on care usually linked to nurses, although including others from medicine and allied health fields. To have a meta-analysis published by these organisations requires submission of a protocol, which is critically reviewed, and revised if necessary. The final review involves following a strict protocol for research identification and analysis, and then production of a final report, again subject to careful internal review before publication. The results are typically conservative, focusing on research with strong methodologies, but provide clear indications of what interventions work for whom. These reviews are frequently used by both individuals, organisations, and guideline authors to determine best practice.

## The role and training of health psychologists

In the light of the significant research conducted by health psychologists, it would seem reasonable that health psychologists should be able to apply their theoretical and practical knowledge within the healthcare system. The profession of health psychologist pursues these goals. According to the British Psychological Society Division of Health Psychology (BPS, undated) the key roles of health psychologists encompass the following:

- *Health promotion and behaviour change*: Promoting health by applying evidence-based interventions for primary prevention of illness or disease, in areas such as healthy eating, physical activity, substance use and sexual health.
- *Health service improvement*: Improving effectiveness of healthcare systems; for instance by increasing uptake of cervical screening.
- *Chronic illness/condition management*: Helping people to deal more effectively with illnesses such as heart disease, diabetes and cancer, including helping them to deal with normal emotional reactions to illness. This can improve their quality of life.
- *Expert advice or consultancy*: Helping health professionals and patients, for example, by gathering evidence to improve services such as pain or weight management.
- *Research*: Health psychologists have advanced skills in a variety of research methods, which enables them to conduct research, provide expert advice or collaborate on a study, for example studying the links between stress and health.
- *Teaching and communication*: This may include training health professionals in a range of intervention skills, for example, how to deliver an intervention to help promote healthy eating or deliver training in communication skills including how to break bad news, or support behaviour change.

In the UK, training to become a health psychologist involves first achieving a good first degree in psychology. After this, the training is to a level equivalent to a PhD: a so-called professional doctorate. Oversight and standards of training programmes are provided by a government body responsible for determining the standards of training for a variety of professions (the Health Care Professions Council). At the time of writing, becoming an accredited health psychologist can be achieved in two ways, both of which involve first obtaining an initial masters level degree in health psychology (called the part 1 qualification) accredited by the British Psychological Society. Following this, trainees must acquire the part 2 qualification in order to be able to act as a health psychology practitioner. This can be obtained through two differing routes, both of which involve trainees gaining the equivalent of two years supervised practice in five areas of competence: (i) generic professional skills, (ii) behaviour change interventions, (iii) research, (iv) consultancy and (v) teaching and training. A number of universities provide a doctoral training programme, completion of which also provides registration with the Health Professions Council and chartered membership of the British Psychological Society. In the so-called 'independent route', trainees organise their own placements, and keep a portfolio of experience which is assessed by an examiner appointed by the British Psychological Society. Trainees also undergo a viva voce examination to ensure their knowledge and competencies across a range of issues and contexts. This provides an equivalent qualification.

Once qualified, the structure of health psychology careers is likely to follow a path similar that below, with indicative roles for each grade within the NHS matching the career structure of other applied psychologists such as clinical or counselling psychologists.

- *Health Psychologist*: Providing health psychology input to a specific healthcare service or services on a one-to-one basis (e.g., diabetes clinics, smoking cessation, cardiac rehabilitation). Psychological assessment of treatment, development, and delivery of tailored interventions and advising on approaches to improve psychological care through working with other health professionals within a multidisciplinary team.
- *Principal Health Psychologist*: Leading a specialist health psychology service within a hospital, providing a clinical service to patients, and advising members of the multidisciplinary team(s). Supervision of junior and trainee psychologists.
- *Consultant Health Psychologist*: As well as having a personal caseload, taking the lead for managing all health psychologists and potentially other professions within a service and developing health psychology within a range of settings including public health and hospitals.

Other roles that may be filled by health psychologist include:

- *Research Psychologist*: Carrying out health psychology research in a range of settings.
- *Health Psychologist in Training/Assistant Health Psychologist*: Assessing
- patients, delivering psychological interventions to change health behaviours and
- conducting research, while being supervised by a qualified health psychologist.

Of note is that while this training and career structure may mirror those of clinical psychology in the UK, the level of training and final degree may differ across countries. In Australia, for example, there is limited training for health psychologists, and this is at a master's degree level. In the Netherlands, while much of the health psychology research conducted in this country is world leading, the professional training of psychologists is much more limited, with no specialism in health psychology, and only limited training in clinical psychology. The tertiary qualification in the Netherlands is at a master's degree level, following a two-year training programme as a healthcare psychologist, whose primary role is work in mental health issues. Many other European countries offer no training analogous to the British programmes.

## Other people 'do' psychology

Even where health psychologists *are* working in healthcare systems, there are still far too few of them to provide a service to all those who may benefit from their work. In addition, many healthcare professionals need to adopt psychologically sophisticated ways of working with patients. Accordingly, the application of the principles of care derived from health psychology research is frequently carried out by health professionals with no immediate alliance to psychology. In the absence of health psychologists, how can we ensure that the research

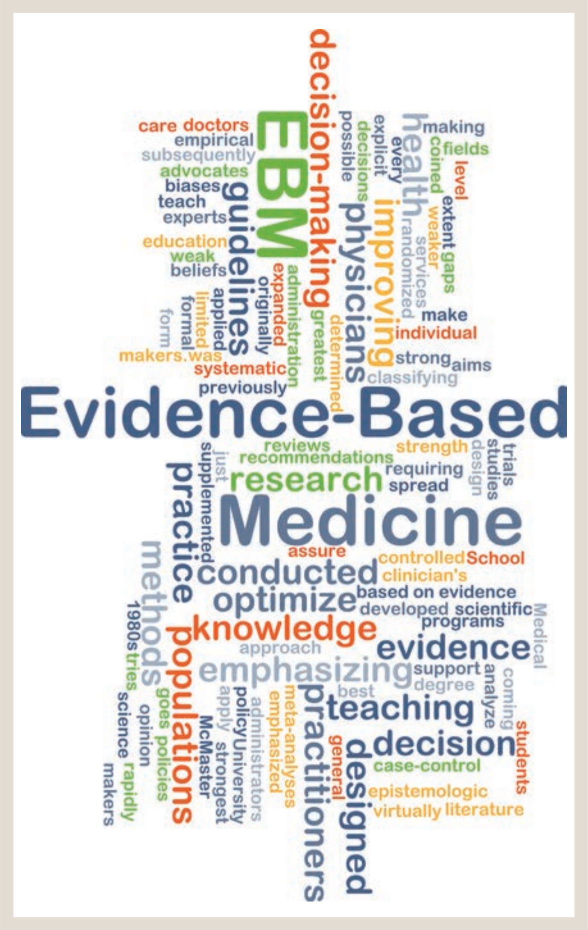


**Photo 18.1** Good quality care is based on evidence and guidelines, not individual health professionals' hunches about 'what works best'.

*Source*: Kheng Guan Toh/123RF.

**CASE STUDY**

## Health psychology in practice

These two job descriptions are examples of job descriptions undertaken by health psychologists.

### 1. Job title: Consultant health psychologist

- *Main roles*: Responsible for developing, leading, managing and providing the psychology service to Cardiac Medicine and Renal Medicine. Provides highly specialist psychological care (including individual and group interventions, consultative advice and supervision for colleagues, education of colleagues and service-based research) for patients with renal disease and coronary heart disease as part of the multi-disciplinary teams. Provides supervision, teaching and training and consultation to other healthcare staff and organisations. Supervises doctoral trainees and newly qualified Clinical and Health psychologists. Member of the Departmental Management Team which provides strategic and operational management of Health Psychology Services. Line-manages staff within the Renal and Cardiac Rehabilitation services. Participates in budgetary planning for the Renal and Cardiac Rehabilitation services.

### 2. Job title: Head of Stop Smoking Services

- *Main roles*: Managing and developing a stop smoking service. Applying research into practice. Determining levels of stop smoking treatment required according to local demand. Managing service budget. Ensuring that there is appropriate training available for health professionals and others regarding smoking cessation. Ensuring that trained staff receive appropriate ongoing professional development. Evaluating existing services and applying changes as necessary. Chairing the Primary Care Trust steering group for smoking cessation. Managing multi-disciplinary team of stop smoking advisers. Providing a health psychology input for other public health initiatives. Providing treatment services to people expressing an interest in stopping smoking. Liaising with other services within the Health Authority and Region to ensure exchange of information and coordinated service provision. Coordinating Continuing Professional Development (training) provision for stop smoking staff within the Health Authority. Working on Pan-London initiatives to promote stop smoking services.

conducted by health psychologists is considered by the wider healthcare system?

One way this can be achieved is through a key role of health psychologists employed within any healthcare system; teaching other professions about health psychology. But how else can this information be disseminated? Unfortunately, at the present time, the answer to this question has to be, ‘with difficulty’. One acknowledged problem in influencing health professionals (including psychologists!) is the communication gap between researchers and practitioners; something that psychological research may particularly suffer from. Most healthcare practitioners and managers rarely read journals which provide cutting-edge research on the delivery of healthcare even within their own discipline. But, for psychology the communication problem may be even more acute. Nurses tend to read nursing journals, doctors read medical journals, and so on. Walk through most hospital libraries and you will not see a psychology journal. Yet most psychological research is published in psychology journals – not medical journals, and not other health professional journals. As Richard Lazarus (2000: 667) noted, ‘The lack of collaboration and communication between researcher and clinician . . . is a familiar and painful topic for most psychologists’. He went on to say that ‘It is disheartening that so few researchers accept the responsibility of making the relevance of their research clear to the practitioner, and so few clinicians pay attention to such research even when it has implications for clinical practice’. Although Lazarus was referring primarily to the situation in the USA, his comments reflect the situation elsewhere in the world.

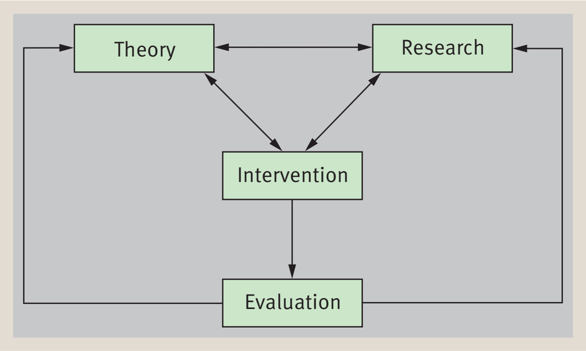


**Figure 18.1** From theory to practice and back again.

*Source*: NHS Centre for Reviews and Dissemination (1999).

If reaching and influencing individual healthcare professionals is difficult, how can psychology influence healthcare? One way is to publish in relevant journals read by the health professionals we are trying to influence. Another is through its influence on higher integrative policies as discussed earlier in the chapter. A number of national psychology and other professional bodies have produced guidelines on psychological care of people with physical health problems. Even more influential than these, though, may be guidelines for care produced by governments and government-sponsored organisations, as discussed earlier in the chapter. The NICE guidelines on strategies of behavioural change considered in Chapter 6 ☛ are a good example of this type of guideline, as are the condition specific guidelines. However, more general guidelines may also be influenced by health psychology. The first page of text of the NICE guidelines for the medical 'treatment of acutely ill patients in hospital' (NICE, 2007c), for example, runs as follows:

- This guideline offers best practice advice on the care of adult patients within the acute hospital setting. Treatment and care should take into account patients' needs and preferences. People with an acute illness should, if appropriate, have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals.
- Good communication between healthcare professionals and patients is essential. It should be supported by evidence-based written information tailored to the patient's needs. Treatment and care, and the information patients are given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English.
- If the patient agrees, carers and relatives should have the opportunity to be involved in decisions about treatment and care. Carers and relatives should also be given the information and support they need.

The type of research reported in Chapter 10 ☛ has clearly contributed to this emphasis on good communication between health professionals and their patients. Health psychology has made a contribution, and an acknowledged contribution, to the care of critically ill patients through its influence on care guidelines. As guidelines develop for the care of patients with a variety of disorders, we can confidently expect psychological care and interventions to be integrated into them. But despite this optimism, our contribution may be far from optimal. And there is even evidence to show that inclusion within guidelines does not guarantee the implementation of any form of care.

## Implementing (or not) clinical guidelines

Unfortunately, even when a fully informed evidence base and written guidelines of best practice exist, and therefore the gap between research and practice has theoretically been bridged, there is no guarantee that they will actually be implemented by the health professions concerned. A starkly discouraging report by Bellhuder and Stanfliet (2014), for example, reported that only 6.2 per cent of requests for blood tests to confirm a diagnosis of myocardial infarction made by a group of hospital doctors followed the correct guidelines. On a more complex process, Jouleh et al. (2018) investigated the degree of adherence to three treatment strands for people with Chronic Obstructive Pulmonary Disease (see Chapter 8 ☛): (i) guideline recommended pharmacological treatment, (ii) provision of influenza vaccination, (iii) providing smoking cessation advice. Complete adherence to the guidelines by doctors was found in only 7 per cent of patients treated in primary care and 30 per cent of those under the care of hospital doctors. Full adherence to the correct medical pharmacological treatment was found in 10 and 36 per cent of patients, respectively. These data are not exceptional. In a review of the relevant literature, Arts et al. (2016) found adherence rates to a range of clinical guidelines to vary between 35 and 91 per cent.

Clearly, promoting adherence to clinical guidelines is not easy, with a range of potential factors contributing to this phenomenon. A number of authors (e.g., Knighton et al., 2019) have highlighted a range of factors that may reduce the uptake of clinical guidelines:

- weaknesses in communicating the evidence base to practitioners;
- conflicting sources of information and opinion being available to practitioners (such as patient preferences, which can contradict global recommendations);
- guidelines that are too complex and difficult to enact or which appear too rigid in ‘real world settings’;
- difficulties in getting the right people to work together to implement change;
- resistance to change amplified by health professionals’ stress levels.
- perceived as having low scientific credibility or poor evidence base;
- difficult to access and not established within the ‘work flow’.

Other factors include:

- *personal attitudes and beliefs* regarding the *target behaviour* (their own and/or the patients’ behaviour), the *treatment* (for example, attitudes towards hormone replacement therapy, child immunisation, abortion) and the *condition* (e.g., obesity, drug use, heart disease, AIDS, chronic fatigue syndrome);
- *personal characteristics of the professional*: age, gender, and cultural values or norms may impact on the willingness to make any required changes.

Given the wide-ranging potential decision points at which any guidelines may fail, it is not surprising that efforts are being made to try to address this situation. Providing research information alone is insufficient to alter practitioner’s health practice (Oxman et al., 1995). However, combining information with reminders about a new guideline can be of benefit. Doherty et al. (2007), for example, reported improvements in various aspects of the treatment of adults with asthma varying from 0 to 26 per cent (deliver therapy via a spacer device), 66 to 84 per cent (use systemic steroids), and 14 to 82 per cent (use written short-term plans) following a mail-out of guideline booklets, and placing posters with flow charts in clinical settings. No changes were found in a hospital that did not receive this intervention. These results show both the existing low levels of adherence to the guidelines and how a relatively simple intervention may markedly increase adherence.

This combination of education and reminders to adhere to the recommended processes was also found to be effective by Smith, Tran and Westra (2016) who improved adherence to the guideline treatment for childhood upper respiratory problems (and in particular the correct prescription of antibiotics) from an already impressive 95 per cent to 98 per cent of cases, following an intervention involving providing an educational update and implementing a clinical decision support system (see Chapter 10 ☛) reminder within the treatment pathway. More systemic changes were suggested by Knighton et al., including:

- Establishing an accurate monitor of adherence levels.
- Ensuring a strong evidence base for any new guidelines and ensuring these are known by the target audience.
- Senior members of the health professionals’ team buy into the changes and provide strong leadership
- All necessary resources are available.
- All health technology challenges can be met.
- Any barriers to deployment are surmountable.

## The need for health psychologists to engage politically

Health psychologists need to engage in appropriate dissemination to healthcare practitioners and, ideally, to policy makers; and need to become better at it. Having greater professional ‘status’ (as a consequence of rigorous training) and the increasing presence of health psychology ‘practitioners’ in healthcare settings, will go some way towards making health psychology voices ‘heard’. This is nowhere better exemplified than in the advisory groups to the UK and other governments, including the Scientific Pandemic Insights Group on Behaviours (SPI-B), and the World Health Organization (WHO, 2020c) established during the COVID-19 pandemic. The so-called nudge unit (https://www.bi.team/) established by the UK government and now an independent ‘social purpose company’ is a longer-term contributor to the influence of psychology on social behaviours beyond those related to health.

In addition to learning how to better ‘sell’ the findings of health psychology research to health professions and policy makers, Murray and Campbell (2003) argued that health psychology needs to broaden its approaches to encompass sociocultural, economic and political aspects of health and healthcare. The perception of psychology, and by default, health psychology, is that we develop and test our theories and methods at an individual level. This traditional narrowness of focus has, Murray and Campbell argued, held back the effectiveness of strategies to improve health on a large scale (such as reducing HIV infection in sub-Saharan Africa, promoting healthier diets in the West), because salient aspects of the micro and macro socio-economic and political environment that act to maintain inequalities in health are ignored (see Chapter 2 ☛). They further noted that health psychology needs to engage in some reflection in order to move forward in a more ‘actionable’ manner. Schwarz and Carpenter (1999, cited in Davey-Smith et al., 2001) also noted that focusing on individual-level determinants of health instead of macro-level determinants (such as income or poverty levels) leads to individualised interventions that fail to address the question, or the solution, appropriately.

## Keep it simple

One key element that has only briefly been touched upon in this chapter is that interventions are more likely to be implemented by both health professionals and their clients if they are relatively simple and easy to implement. One of the authors of this book (PB) was made acutely aware of this in a discussion with colleagues in an academic department of General Practice in which he was working at the time. He was thinking of evaluating the effectiveness of an intervention targeted at depressed cardiac patients to see whether it would reduce both depression and the incidence of recurrent myocardial infarction (see Chapter 17 ☛). The discussion revolved around whether it would be better to run the groups in the weeks immediately after the intervention (and therefore prevent any depression becoming chronic, but risk treating people who would naturally recover without any intervention) or wait for six months and treat people whose depression had become chronic (and potentially harder to treat). Unfortunately, the debate was rather cut short when one of the GPs noted that even if such an intervention were to work, there are so few psychologists who would be able to run such groups (and no likely funding within the NHS) that no GP would be able to send their patients to it! As a result of this discussion, PB went on to develop a highly effective one-page written intervention, based around active distraction, designed to reduce distress in women undergoing genetic risk assessment (Bennett et al., 2007).

### WHAT DO YOU THINK?

So, what do you think? Should psychologists attempt to influence key players both in healthcare and other spheres? And if so, how? What can individuals do to disseminate good psychological practice? And what should academic and professional bodies do to promote the discipline? Who are the key players psychologists should influence? Should they seek allies in other health professions, such as medics, nurses or occupational therapists, disciplines for which psychology is a core element of their work? Should we influence people we work with, politicians, leaders of health services, or others? Who would you target as people or positions to influence, and how would you set about this? The reality is that influence through these systems is not easy. But should we be trying as individual practitioners, as a society of psychologists through vehicles such as the British Psychological Society, or should we leave this influence to others?

Whatever the impact of this discussion on PB’s career, the discussion held a key truth. Psychologists and others can develop many and complex interventions, but unless they are implementable within the context of a busy, and tightly resourced healthcare service (as they all are), they will not be adopted by healthcare professionals, and managers will not fund them. Interventions such as the Recurrent Coronary Prevention Program (which worked) and the ENRICHD study (which didn’t) described in Chapter 17 ☛ may show the potential impact of complex and extended psychological interventions on health. But even if both had proved enormously successful, neither would be implemented in most existing health services. Interventions such as establishing implementation intentions (as discussed in Chapter 6 ☛) or using simple distraction techniques to reduce worry may be less glamorous than these hugely expensive multi-factorial studies, but they may ultimately be of more benefit. The issue that has to be considered when developing any intervention is not only is it effective, but also is it *cost-effective*? Because only if it is cost-effective will both healthcare providers and bodies that provide guidance to healthcare providers (such as NICE) endorse the use of such interventions. Accordingly, health psychologists may usefully concentrate on this type of intervention if they want their interventions to be of value in the healthcare system.

## . . . and finally, be positive

While this textbook, and this chapter in particular, has highlighted many of the challenges faced by our discipline and profession, it has highlighted the many domains in which health psychology has contributed significantly to understanding (e.g. health behaviour and behaviour change, stress and coping, illness processes and outcomes, psychosocial interventions). There is much to be positive about, but clearly not complacent, and many questions remain. For example, do implementation intentions work in clinical samples? Do stage-based activity interventions work in the long term? Does coping really make a difference? Much of health psychology tends to focus on problems – preventing illness, coping with illness, and so on. As well as being optimistic in ourselves, we can also learn from developments in the field of 'positive psychology' (e.g. Seligman and Csikszentmihalyi, 2000), which bring with them many other opportunities for health psychology to strengthen its evidence base – see Chapters 11, 12 and 17 ☛.

Research in the 'positive psychology' tradition has shown that out of many potentially negative situations come positives (for example, reaffirmed love, or the discovery of unknown personal strengths, caused by entering a spousal caring role), and that positive affect and the finding of 'meaning' in stressful situations can be adaptational (e.g. Folkman and Moscowitz, 2000). Underlying many psychosocial interventions to improve adjustment or behavioural change has been the assumption that certain stressors (e.g. illness, caring) inevitably elicit negative affect and cognition, and that these need to be reduced in order to improve outcome. In contrast, positive psychology encourages thinking to turn to enhancement of positive affect (particularly that which is congruent with one's current situation), such as hope or optimism in a situation where goals are attainable, humour or positive reappraisal where goals are not so easily reached.

**Photo 18.2** To make an increasing difference to the health of our nations, health psychologists need to disseminate their findings to a wide audience, including health professionals, educators and policy makers.

*Source*: Hxdbzxy/Shutterstock.

A good example of how health psychology may provide a biased or distorted view of the impact of health problems can be found in the work examining the impact of cancer genetic risk identification. The work here has consistently found that around one-quarter of the women that undergo assessment for their risk of breast/ovarian cancer experience significant distress (see Chapter 6 ☛). However, a study of this group conducted by one of the authors (PB) found that the most highly endorsed emotional responses to this process included anxiety, but also included the more positive emotions related to hope, challenge and optimism. The neglect of such issues means we run the risk of pathologising many of the phenomena we study, and ignore many of the positive and human aspects they bring. Furthermore, in the area of preventive health, health psychology research has identified 'protective' factors for health as well as risk factors for morbidity. Think, for example, of the research supporting positive associations between social support, or optimism, and positive adjustment to stressful events. Such findings provide opportunities for interventions that are quite different in emphasis from those offered by the findings of negative associations between hostility, stress responses and coronary heart disease. We must not fall into the trap of assuming that we can only advise on 'what not to do'.

Health psychology will not stand still. Its contribution to the health of society is likely to grow as our knowledge base and our confidence in it grows, and as external bodies grow in confidence as to the important role psychology has to play in relation to health. Keep in touch via our website.

## SUMMARY

This final chapter has attempted to draw together much of the work described in this book and to give the reader a picture of the ways in which health psychology research can contribute to health practice. Although health psychology is a theory-led discipline, its goals are applied, and we have attempted in this chapter to make the links between theory and practice evident. In addition, we have noted that there is a need for health psychologists to engage more politically and to 'sell' themselves and their (cost-effective) 'goods' more effectively to policy makers and health practitioners. In doing so, we would hope to maximise the impact of health psychology as a discipline upon health psychology as a practice. Our final aim should be to strengthen the links between health psychology and health professional practice in order to benefit all of us, who will at some point in our lives enter the healthcare system.

## Further reading

Beard, E., West, R., Lorencatto, F., Gardner, B., Michie, S., Owens, L. and Shahab, L. (2019). What do cost-effective health behaviour-change interventions contain? A comparison of six domains. *PloS one*, 14(4), e0213983.

An introduction to the idea of the behaviour change taxonomy and how it can be used to determine the most cost-effective psychology interventions.

King, K.M., Pullmann, M.D., Lyon, A.R. et al. (2019). Using implementation science to close the gap between the optimal and typical practice of quantitative methods in clinical science. *Journal of Abnormal Psychology*, 128: 547–562.

So problematic has been the gap between research and practice, a new form of academic approach has been taken to research and influence this process. Implementation science is emerging as an important

In addition to these static texts, it may be interesting to go to websites describing developments in the profession of health psychology. Some examples of such sites (extant in 2021) are:

The Australian Psychological Society:

https://groups.psychology.org.au/chp/

The British Psychological Society:

https://careers.bps.org.uk/area/health

https://careers.bps.org.uk/area/health/how-do-i-become-one

Some sources of published clinical guidelines. These are central government resourced guideline resources. Other guidelines may be produced by (usually) specific medical organisations involved in the treatment of specific disorders. Psychology guidelines tend to be more general, and not specific to conditions or types of intervention. Key national agencies providing guidelines are:

www.nice.org.uk/ (England, Wales, Northern Ireland)

https://www.sign.ac.uk/ (Scotland)

www.guideline.gov/ (USA)

Visit the website at **go.pearson.com/uk/he/resources** for additional resources to help you with your study.

# Glossary

**(to) catastrophise** evoke an exaggerated negative attribution/expectation of a situation: 'This pain means something is seriously wrong!'

## A

**acceptance coping** accepting the reality of a situation and that it cannot easily be changed

**ACE inhibitors** angiotensin II causes the muscles surrounding blood vessels to contract and thereby narrows the blood vessels. Angiotensin Converting Enzyme (ACE) inhibitors decrease the production of angiotensin II, allowing blood vessels to dilate, and reduce blood pressure.

**acetylcholine** a neurotransmitter responsible for muscle activation and involved in attention and arousal

**adrenal glands** endocrine glands, located above each kidney; comprise the cortex, which secretes several steroid hormones, and the medulla, which secretes noradrenaline

**adrenaline** a neurotransmitter and hormone secreted by the adrenal medulla that increases physiological activity in the body, including stimulation of heart action and an increase in blood pressure and metabolic rate; also known as epinephrine

**aetiology** (etiology): the cause of disease

**affective** to do with affect or mood and emotions

**agonist** a drug that simulates the effects of neurotransmitters, such as the serotonin agonist fluoxetine, which induces satiety (reduces hunger)

**ambivalence** the simultaneous existence of mixed thoughts and feelings towards an attitude object, person or event i.e. simultaneously holding, both positive and negative evaluations

**ambulatory blood pressure** blood pressure measured over a period of time using an automatic blood pressure monitor which can measure blood pressure while the individual wearing it engages in their everyday activities

**amygdala** part of the limbic system involved in the processing of memory, decision making, and emotional responses (including fear, anxiety, and aggression); ometimes known as the 'fear centre' of the brain

**angina** severe pain in the chest associated with a temporary insufficient supply of blood to the heart.

**antibodies** immunoglobulins produced in response to an antigen

**antigen** unique product found on the surface of a pathogen that enables the immune system to recognise that pathogen as a foreign substance and therefore produce antibodies to fight it; vaccinations introduce specially prepared viruses or bacteria into a body, and these have antigens

**antioxidants** oxidation of low-density lipoprotein (LDL or 'bad') cholesterol has been shown to be important in the development of fatty deposits in the arteries; antioxidants are chemical properties (polyphenols) of some substances (e.g. red wine) thought to inhibit the process of oxidation

**aorta** the main trunk of the systemic arteries, carrying blood from the left side of the heart to the arteries of all limbs and organs except the lungs

**aphasia** inability (or impaired ability) to understand or produce speech, as a result of brain damage

**appraisals** interpretations of situations, events or behaviour that a person makes

**apraxia** inability to perform particular purposive actions

**arteriosclerosis** loss of elasticity and hardening of the arteries

**atheroma** fatty deposit in the intima (inner lining) of an artery

**atherosclerosis** formation of fatty plaque in the arteries

**atrial fibrillation** a heart rhythm disorder (arrhythmia); it involves a very rapid heart rate, in which the atria (upper chambers of the heart) contract in a very rapid and disorganised manner and fail to pump blood effectively through the heart

**attention** generally refers to the selection of some stimuli over others for internal processing

**attributions** a person's perceptions of what causes beliefs, feelings, behaviour and actions (based on attribution theory)

**autoimmune conditions** a group of diseases, including type 1 diabetes, Crohn's disease and rheumatoid arthritis, characterised by abnormal functioning of the immune system in which it produces antibodies against its own tissues – it treats 'self' as 'non-self'

**avoidant coping** a style of coping that involves emotional regulation by avoiding confrontation with a stressful situation; analagous to emotion-focused coping

## B

**B cell** a form of lymphocyte involved in destruction of antigens. Memory B cells provide long-term immunity against previously encountered pathogens.

**bad news interview** conversation between health professional (usually a doctor) and patient in which they are told 'bad news', usually that their illness has a very poor prognosis, and they may die

**baroreceptors** sensory nerve endings that are stimulated by changes in pressure; located in the walls of blood vessels such as the carotid sinus

**behavioural immunogen** a behavioural practice considered to be health-protective, e.g. exercise

**behavioural pathogen** a behavioural practice thought to be damaging to health, e.g. smoking

**behaviourism** this approach emphasises objectifiable actions and the environmental factors that shape action/ behaviour (c.f. Skinner, classical conditioning)

**benefit finding** a process of finding beneficial outcomes as a consequence of what is normally seen as a negative event, such as developing cancer or being infected with HIV

**beta-blockers** block the action of adrenaline and noradrenaline on b-adrenergic receptors, which mediate the 'fight or flight' response, within the heart and in muscles surrounding the arteries. In doing so, they reduce increases in blood pressure associated with sympathetic activation.

**bile** a digestive juice, made in the liver and stored in the gallbladder; involved in the digestion of fats in the small intestine

**biofeedback** technique of using monitoring devices to provide information regarding an autonomic bodily function, such as heart rate or blood pressure; used in an attempt to gain some voluntary control over that function

**biomedical model** a view that diseases and symptoms have an underlying physiological explanation

**biopsychosocial** a view that diseases and symptoms can be explained by a combination of physical, social, cultural and psychological factors (cf. Engel 1977)

**blunters** this general coping style involves minimising or avoiding the source of threat or stress, i.e. avoiding threat-relevant information (as opposed to monitors)

**body mass index** a measure of weight in relation to height; allows a calculation of how heavy an individual is 'for their height' and mass determines whether an individual is over or under weight

## C

**carcinogenic/ carcinogenesis** substances implicated in the development of cancer cells/ the process by which normal cells become cancer cells (i.e. carcinoma)

**cardiac event** generic term for a variety of end points of coronary heart disease, including a myocardial infarction, angina and cardiac arrest

**cardiovascular** pertaining to the heart and blood vessels

**carotid artery** the main artery that takes blood from the heart via the neck to the brain

**carotid plaque** a plaque is a thick waxy coating which forms on blood vessel walls and restricts blood flow, in this instance in the carotid artery

**catecholamines** these chemical substances are brain neurotransmitters and include adrenaline and noradrenaline

**causal attribution** where a person attributes the cause of an event, feeling or action to themselves, to others, to chance or to some other causal agent

**CD4+ cells** otherwise known as helper T cells, these are involved in the proliferation of cytotoxic T cells as part of the immune response; HIV infection impairs their ability to provide this function

**cell suicide** a form of cell death in which a controlled sequence of events (or programme) leads to the elimination of cells without releasing harmful substances into the surrounding area

**central nervous system** that part of the nervous system consisting of the brain and spinal cord

**cervical smear** a procedure involving taking a smear of cellular material from the neck (cervix) of the uterus for detection of cancer

**chronic bronchitis** an inflammation of the bronchi, the main air passages in the lungs, which persists for a long period or repeatedly recurs; characterised by excessive bronchial mucus and a cough

**chronic obstructive pulmonary (airways) disease** a persistent airway obstruction associated with combinations of chronic bronchitis, small airways disease, asthma and emphysema

**clot busters** drugs which dissolve clots associated with myocardial infarction and can prevent damage to the heart following such an event. Are best used within one hour of the infarction

**cognitive dissonance** where a person holds thoughts that are inconsistent with each other and which causes discomfort that a person may try to resolve through seeking information in support of one belief, or by ignoring or changing one's belief/attitude

**cognitive restructuring** a reconsideration of automatic negative or catastrophic thoughts to make them more in line with reality

**cognitive schemata** set of unconscious beliefs about the world and ourselves that shape more conscious cognitive responses to events that impinge on us

**cold pressor test** procedure in which participants place their arm in a mixture of water and ice with a water temperature of between 0 and 3 degrees centigrade

**collectivist** a cultural philosophy that emphasises the individual as part of a wider unit and places emphasis on duties above rights, with actions motivated by interconnectedness, reciprocity and group membership, rather than individual needs and wants

**colonoscopy** a minor surgical procedure in which a small piece of bowel wall is cut from the colon; this can then be tested for the presence of malignant cells

**colostomy** a surgical procedure that creates an opening (stoma) in the abdomen for the drainage of stool from the large intestine (colon); it may be temporary or permanent

**colposcopy** a procedure carried to closely examine the cervix, vagina and vulva for signs of disease; it may involve taking a deeper biopsy that would occur in a cervical smear

**comparative optimism** initially termed 'unrealistic optimism', this term describes an individual's estimate of their risk of experiencing a negative event compared with similar others (Weinstein and Klein, 1996)

**conditioning theory** the theory that behaviour is directly influenced/reinforced by its consequences, positive and negative

**coronary angioplasty** a procedure where a small balloon is inserted into the blocked coronary artery of a person with atheroma

**coronary artery bypass graft** surgical procedure in which veins or arteries from elsewhere in the patient's body are grafted from the aorta to the coronary arteries, bypassing blockages caused by atheroma in the cardiac arteries and improving the blood supply to the heart muscle

**coronary heart disease** a narrowing of the blood vessels that supply blood and oxygen to the heart; results from a build-up of fatty material and plaque (atherosclerosis); can result in angina or myocardial infarction

**coronavirus** one of a group of RNA viruses that cause a variety of diseases – most recently SARS-CoV-2 virus has caused COVID-19 disease (SARS: severe acute respiratory syndrome)

**corticosteroids** powerful anti-inflammatory hormones (including cortisol) made naturally in the body or synthetically for use as drugs

**cortisol** a stress hormone that increases the availability of energy stores and fats to fuel periods of high physiological activity; it also inhibits inflammation of damaged tissue

**C-reactive protein** a marker of immune activation associated with high levels of stress and infection

**Crohn's disease** autoimmune disease that can affect any part of the gastrointestinal tract but most commonly occurs in the ileum (the area where the small and large intestine meet)

**cross-sectional design** a study that collects data from a sample on one occasion only; ideally, the sample should be selected to be representative of the population under study.

## D

**decisional balance** where the costs (cons) of behaviour are weighed up against the benefits (pros) of that behaviour

**defibrillator** a machine that uses an electric current to stop any irregular and dangerous activity of the heart's muscles. It can be used when the heart has stopped (cardiac arrest) or when it is beating in a highly irregular (and ineffective) manner

**diabetes (type 1 and 2)** a lifelong disease marked by high levels of sugar in the blood and a failure to transfer this to organs that need it. It can be caused by too little insulin (type 1), resistance to insulin (type 2), or both

**diastolic blood pressure** the minimum pressure of the blood on the walls of the arteries between heartbeats (measured in relation to **systolic blood pressure**)

**dispositional pessimism** having a generally negative outlook on life and a tendency to anticipate negative outcomes (as opposed to dispositional optimism)

**distancing response** taking a detached view, often a scientific view, of an event or stimulus in order to reduce emotional activation

**diuretics** elevates the rate of bodily urine excretion, reducing the amount of fluid within the cardiovascular system, and reducing pressure within it

**dualism** the idea that the mind and body are separate entities (cf. Descartes)

**dysarthria** difficulty speaking caused by problems controlling the muscles used in speech

**dysphasia** language disorder marked by deficiency in the generation of speech, and sometimes also in its comprehension

## E

**efficacy** Bandura's technical term analogous to confidence

**egocentric** self-centred, such as in the preoperational stage (age 2–7 years) of children, when they see things only from their own perspective (cf. Piaget)

**emotion-focused coping** coping that seeks to manage the emotional response to the stressor

**emphysema** a late effect of chronic infection or irritation of the bronchial tubes; when the bronchi become irritated, some of the airways may become obstructed or the walls of the tiny air sacs may tear, trapping air in the lung beyond them – as a result, the lungs may become enlarged, at the same time becoming less efficient in exchanging oxygen for carbon dioxide

**empiricism** arising from a school of thought that all knowledge can be obtained through experience

**endocrine glands** glands that produce and secrete hormones into the blood or lymph systems; includes the pituitary and adrenal glands, and the islets of Langerhans in the pancreas; these hormones may affect one organ or tissue, or the entire body

**endorphins** naturally occurring opiate-like chemicals released in the brain and spinal cord, they reduce the experience of pain and can induce feelings of relaxation or pleasure; associated with the so-called 'runner's high'

**epidemiology** the study of patterns of disease in various populations and the association with other factors such as lifestyle factors; key concepts include mortality, morbidity, prevalence, incidence, absolute risk and relative risk. Type of question: Who gets this disease? How common is it?

**erythrocyte** a mature blood cell that contains haemoglobin to carry oxygen to the bodily tissues

**eudaemonic** the goal of life should be to live as one's true self, to strive for meaning, personal growth and self-actualisation, with a focus on psychological wellbeing

**exercise programme** a key element of most cardiac rehabilitation, including a progressive increase in exercise usually starting in a gym, sometimes developing into exercise in the home and beyond

**exogenous** relating to things outside the body

**exosystem** where individuals are affected by systems they are not part of, for example a partner's inflexible workplace policies, media coverage of a health issue

**expressed emotion** the disclosure of emotional experiences as a means of reducing stress; often achieved by describing the experience in writing

## F

**factor analysis** a method of analysis which seeks to reduce relationships between a wide set of correlated items into meaningful groups, or factors

**fistulas** formation of small passages that connect the intestine with other organs or the skin

## G

**gallbladder** a structure on the underside of the liver on the right side of the abdomen, it stores the bile that is produced in the liver before it is secreted into the intestines; this helps the body to digest fats

**gate control theory of pain** a theory of pain developed by Melzack and Wall in which a 'gate' is used as a metaphor for the chemicals, including endorphins, that mitigate the experience of pain

**general adaptation syndrome** a sequence of physiological responses to prolonged stress, from the alarm stage through the resistance stage to exhaustion

## H

**haemoglobin** the main substance of the red blood cell; when oxygenated in the lungs, it is converted to oxyhaemoglobin, thus allowing the red blood cells to carry oxygen from the air in our lungs to all parts of the body

**health behaviour** behaviour performed by an individual, regardless of their health status, as a means of protecting, promoting or maintaining health, e.g. diet

**health differential** a term used to denote differences in health status and life expectancy across different groups

**health hardiness** the extent to which a person is committed to and involved in health-relevant activities, perceives control over their health and responds to health stressors as challenges or opportunities for growth

**health locus of control** the perception that one's health is under personal control; controlled by powerful others such as health professionals; or under the control of external factors such as fate or luck

**heart failure** a state in which the heart muscle is damaged or weakened and is unable to generate a cardiac output sufficient to meet the demands of the body

**hedonic** the goal of living is to maximise happiness and pleasure and minimise negative affect, with a focus on subjective wellbeing and life satisfaction

**hemianopia** blindness in half the visual field of one or both eyes

**hemiparesis** weakness on one side of the body

**hemiplegia** inability to move one side of the body

**high-density lipoprotein (HDL)** lipoproteins are fat protein complexes in the blood that transport cholesterol, triglycerides and other lipids to various tissues; the main function of HDL appears to be to carry excess cholesterol to the liver for 're-packaging' or excretion in the bile; higher levels of HDL seem to be protective against CHD, so HDL is sometimes referred to as 'good' cholesterol

**human papillomavirus (HPV)** a family of over 100 viruses, of which 30 types can cause genital warts and be transmitted by sexual contact; while most genital HPV come and go over the course of a few years, two specific HPV types markedly elevate the risk for cancer of the cervix

**humanism** this approach emphasises the inner feelings and needs of individuals (c.f. Rogers, Maslow)

**hypoglycaemic episode** occurs when the body's glucose level is too low; frequently occurs when too much insulin or oral diabetic medication is taken, not enough food is eaten, or following exercise without appropriate food intake – symptoms include excessive sweating, paleness, fainting and eventually loss of consciousness

**hypothalamus** area of the brain that regulates appetite, sexual arousal and thirst. Also appears to have some control over emotions

## I

**illicit drugs** includes illegal substances, but also legal substances that are used illicitly, i.e. in ways other than intended e.g. sniffing glue, injecting valium

**illness behaviour** characterises a person who is sick and who seeks a remedy, e.g. taking medication; usually precedes formal diagnosis after which behaviour is described as sick role behaviour

**illness cognition** the cognitive processes involved in a person's perception or interpretation of symptoms or illness and how they represent it to themselves (or to others) (cf. Croyle and Ditto 1990)

**illness representations** beliefs about a particular illness and state of ill health – commonly ascribed to the five domains described by Leventhal: identity, timeline, cause, consequences and control/cure

**implicit attitude** attitudes that activate unintentionally in response to actual or symbolic presence of an attitude-object (stimulus) and which therefore don't require the cognitive effort of explicit attitudes

**incidence** the number of new cases of disease occurring during a defined time interval – not to be confused with prevalence, which refers to the number of established cases of a disease in a population at any one time

**individual differences** aspects of an individual that distinguish them from other individuals or groups (e.g. age, personality

**individualistic** a cultural philosophy that places responsibility at the feet of the individual and emphasises rights above duties; thus behaviour is often driven by individual needs and wants rather than by community needs or wants

**inflammatory bowel disease** a group of inflammatory conditions of the large intestine and, in some cases, the small intestine; the main forms of IBD are **Crohn's disease** and **ulcerative colitis**

**irritable bowel syndrome** a disorder of the lower intestinal tract; symptoms include pain combined with altered bowel habits resulting in diarrhoea, constipation or both; it has no obvious physiological abnormalities, so diagnosis is by the presence and pattern of symptoms

**ischaemic heart disease** a heart disease caused by a restriction of blood flow to the heart

**ischaemic pain** pain due to lack of blood supply to the muscles

## K

**Kaposi's sarcoma** a malignant tumour of the connective tissue, often associated with AIDS. The tumours consist of bluish-red or purple lesions on the skin; they often appear first on the feet or ankles, thighs, arms, hands and face

## L

**lay referral system** an informal network of individuals (e.g. friends, family, colleagues) turned to for advice or information about symptoms and other health-related matters; often (but not only) used before seeking a formal medical opinion

**life events** a term used to describe occurrences in a person's life which may be viewed positively or negatively but which inherently require some adjustment on the part of the person (e.g. marriage, loss of job). Such events are implicated in the experience of stress

**limbic system** a series of structures in the brain, often referred to as the 'emotional computer' because of its role in coordinating emotions; it links sensory information to emotionally relevant behaviour, in particular responses to fear and anger – includes the hippocampus, amygdala, anterior thalamic nuclei, septum and limbic cortex

**locus of control** a personality trait thought to distinguish between those who attribute responsibility for events to themselves (i.e. internal LoC) or to external factors (external LoC)

**low-density lipoprotein (LDL)** the main function of LDL seems to be to carry cholesterol to various tissues throughout the body; LDL is sometimes referred to as 'bad' cholesterol because elevated levels of LDL correlate most directly with coronary heart disease

**lower respiratory tract infection** infection of the parts of the respiratory system including the larynx, trachea, bronchi and lungs

**lumpectomy** a surgical procedure in which only the tumour and a small area of surrounding tissue are removed. Contrasts with mastectomy in which the whole breast is removed

**lymphocyte** a type of white blood cell. Lymphocytes have a number of roles in the immune system, including the production of antibodies and other substances that fight infection and disease; includes T and B cells

## M

**macrosystem** a person's wider setting including socioeconomic, environmental and cultural factors that frame the structures and relationships between all other systems

**mammography** a low-dose X-ray procedure that creates an image of the breast. The X-ray image can be used to identify early stages of tumours

**mechanistic** a reductionist approach that reduces behaviour to the level of the organ or physical function – associated with the **biomedical model**

**mediate/mediator** mediating variables explain how or why a relationship exists between two other variables: for example, the effects of age upon behaviour may be mediated by health beliefs; thus age effects would be said to be indirect, rather than direct

**melanoma** a form of skin cancer. Usually begins in a mole and has a poor prognosis unless treated

**mesosystem** where multiple aspects of a person's microsystem interconnect and act upon the individual, for example communications between a person's family member and a healthcare provider

**meta-analysis** a review and re-analysis of pre-existing quantitative datasets that combines the analysis so as to provide large samples and high statistical power from which to draw reliable conclusions about specific effects

**metabolic syndrome** the presence of three of: central obesity, high blood pressure, high blood sugar, high serum triglycerides, low serum high-density lipoprotein. These increase risk of cardiovascular disease and type 2 diabetes

**microsystem** a person's immediate direct contacts including family, friends, class mates or colleagues

**migraine** a headache with symptoms including nausea, vomiting or sensitivity to light; associated with changes in vascular flow within the brain

**mirroring** a therapeutic technique in which the therapist repeats back to a client, usually as a paraphrase but sometimes word for word, the idea that has just been expressed

**moderator/moderation** moderating variables explain the conditions under which a relationship between two other variables may exist: for example, the relationship between individual beliefs and behaviour may be different depending on gender or health status

**monist** the idea that the non-physical mind cannot be studied separately from the physical brain

**monitors** this generalised coping style involves attending to the source of stress or threat and trying to deal with it directly, e.g. through information-gathering/attending to threat-relevant information (as opposed to blunters)

**morbidity** costs associated with illness such as disability, injury

**mortality** (death): generally presented as mortality statistics, i.e. the number of deaths in a given population and/or in a given year ascribed to a given condition (e.g. number of cancer deaths among women in 2000)

**motivation** memories, thoughts, experiences, needs and preferences that act together to influence (drive) the type, strength and persistence of our actions

**multiple sclerosis** a disorder of the brain and spinal cord caused by progressive damage to the myelin sheath covering of nerve cells

**myelin sheath** a substance that contains both protein and fat (lipid) and surrounds all nerves outside the brain; it acts as a nerve insulator and helps in the transmission of nerve signals

**myocardial infaction** (aka, heart attack): death of heart muscle due to lack of oxygen; this results from an obstruction in blood supply due to a clot blocking one or more arteries supplying the heart with oxygen

## N

**natural killer (NK) cells** cells that move in the blood and attack cancer cells and virus-infected body cells

**negative affectivity** a dispositional tendency to experience persistent and pervasive negative or low mood and self-concept (related to neuroticism)

**neophobia** a persistent and chronic fear of anything new (places, events, people, objects)

**neuroticism** a personality trait reflected in the tendency to be anxious, feel guilty and experience generally negative thought patterns

**neurotransmitter** a chemical messenger (e.g. adrenaline, acetylcholine) used to communicate between neurons and other neurons and other types of cell

**nocebo effect/response** the opposite of the placebo effect, from the Latin 'to harm' it describes a situation where a negative outcome or experience is reported due to a person's belief that they have been exposed to something harmful

**noradrenaline** this **catecholamine** is a neurotransmitter found in the brain and in the **sympathetic nervous system**; also known as **norepinephrine**

## O

**objective** i.e. real, visible or systematically measurable (e.g. adrenaline levels). Generally pertains to something that can be seen, or recorded, by others (as opposed to subjective)

**observational studies** research studies which evaluate the effects of an intervention (or a treatment) without comparison to a control group and thus such studies are more limited in their conclusions than randomised controlled trials

**operant conditioning** attributed to Skinner, this theory is based on the assumption that behaviour is directly influenced by its consequences (e.g. rewards, punishments, avoidance of negative outcomes)

**oral hypoglycaemic agents** various drug types, all of which reduce circulating blood glucose levels

**outcome expectancies** the outcome that is expected to result from behaviour, e.g. exercise will make me fitter

**oxytocin** this hormone which also acts as a neurotransmitter in the brain appears to attenuate (reduce) autonomic stress responses and may be associated with affiliative social behaviour

## P

**pain threshold** the minimum amount of pain intensity required before it is detected (individual variation)

**pancreas** gland in which the islets of Langerhans produce insulin; also produces and secretes digestive enzymes; located behind the stomach

**parasympathetic nervous system** arm of the autonomic nervous system that is responsible for rest and recuperation

**patient-controlled analgesia (PCA)** a technique through which small doses of analgesic drugs, usually opioids, are administered (usually by an intravenous drip and controlled by a pump) by patients themselves; it is mostly used for the control of postoperative pain

**perceived behavioural control** one's belief in personal control over a certain specific action or behaviour

**phagocyte** an immune system cell that can surround and kill micro-organisms and remove dead cells; phagocytes include macrophages

**phantom limb pain** a phenomenon that occurs following amputation of a limb, in which the individual feels like they still have their limb, and the limb is in pain

**placebo intervention** an intervention designed to simulate a psychological intervention but not believed to be a specific therapy for the target condition

**placebo response** from the Latin 'to please' this describes a situation where a positive outcome or experience is reported in spite of receiving an inactive substance or intervention

**platelets** tiny bits of protoplasm found in the blood that are essential for blood clotting; these cells bind together to form a clot and prevent bleeding at the site of injury

**post-traumatic growth** following a traumatic event, including serious illness, a person may experience positive psychological change, e.g. increased life appreciation, improved relations to self and others, new life values and priorities

**post-traumatic stress disorder** a disorder that forms a response to experiencing a traumatic event. The key elements are unwanted repetitive memories of the event, often in the form of flashbacks, attempts at avoidance of such memories, and a generally raised level of arousal

**predisposition** predisposing factors increase the likelihood of a person engaging in a particular behaviour, such as genetic influences on alcohol consumption

**premature mortality** death before the age it is normally expected. Usually set at deaths under the age of 65 years

**primary prevention** intervention aimed at changing risk factors prior to disease development

**proactive coping** the process of anticipating potential stressors and acting in advance either to prevent them or to minimise their impact

**problem-focused coping** coping that seeks to reduce the demands of the stressor or increase one's resources to deal with it

**prognosis** the predicted outcome of a disease

**prosocial behaviour** behavioural acts that are positively valued by society and that may elicit positive social consequences

**psychosocial** an approach that seeks to merge a psychological (more micro- and individually oriented) approach with a social approach (macro-, more community- and interaction-oriented), for example, to health

## Q

**qualitative methods** concerned with describing (qualifying) the experience, beliefs and behaviour of a particular group of people

## R

**radical prostatectomy** otherwise known as a total prostatectomy, this involves using surgery to remove all of the prostate as a cure for prostate cancer

**reflection** involves listening to and feeding back understandings of the feelings of an individual, rather than simply the content of their statements

**reinforcers** factors that reward or provide a positive response following a particular behaviour or set of behaviours (positive reinforcer); or enable the removal or avoidance of an undesired state or response (negative reinforcer)

**repression** a defensive coping style that serves to protect the person from negative memories or anxiety-producing thoughts by preventing their gaining access to consciousness

**response shift** changes in subjective reports that may result from a reprioritisation of life expectations or recalibration of internal standards so that the construct being assessed is reconceptualised

**rheumatoid arthritis** a chronic autoimmune disease with inflammation of the joints and marked deformities

## S

**salience** strength and importance

**sciatica** pain down the leg, which is caused by irritation of the main nerve into the leg, the sciatic nerve; this pain tends to be caused where the nerves pass through and emerge from the lower bones of the spine (lumbar vertebrae)

**self-concept** that knowledge, conscious thoughts and beliefs about yourself that allow you to feel you are distinct from others and that you exist as a separate person

**self-determination theory** this theory considers the extent to which behaviour is self-motivated (i.e. by intrinsic factors) and influenced by the core needs of autonomy, competence and psychological relatedness

**self-efficacy** the belief that one can perform particular behaviour in a given set of circumstances

**self-regulation** the process by which individuals monitor and adjust their behaviour, thoughts and emotions in order to maintain a balance or a sense of normal function

**self-talk** talking to oneself (internally) – can be negative and thus add to stress; therapeutically, individuals are taught to use self-talk in a way that helps them to keep calm

**sensitivity (of a test)** the ratio of true positive tests to the total number of positive cases expressed as a percentage; for example, a sensitive test may have 95 per cent success in detecting a disease among patients known to have that disease; a test with high sensitivity has few false negatives

**sick role behaviour** the activities undertaken by a person diagnosed as sick in order to try to get well

**social capital** social capital (often includes cultural and economic capital) is gained from the networks around people and communities that engender reciprocity, trust, participation and cooperation (Coleman, 1988; Putnam, 2001)

**social cognition theory** a model of social knowledge and behaviour that highlights the explanatory role of cognitive factors (e.g. beliefs and attitudes)

**social comparison** the process by which a person or group of people compare themselves (their behaviour or characteristics) with others

**social desirability bias** the tendency to answer questions about oneself or one's behaviour in a way that is thought likely to meet with social (or interviewer) approval

**social exclusion** a multidimensional process through which individuals become disengaged from mainstream society, depriving people of the rights, resources and services available to the majority

**social learning theory** a theory that has at its core the belief that a combination of outcome expectancy and outcome value will shape subsequent behaviour; reinforcement is an important predictor of future behaviour

**socialisation** the process by which a person learns – from family, teachers, peers – the rules, norms and moral codes of behaviour expected of them

**socio-economic status** a measure of the social class of an individual; different measures use different indicators, including income, job type or years of education; higher status implies a higher salary or higher job status

**specificity (of a test)** the ratio of true negative tests to the total number of negative cases expressed as a percentage; for example, healthy people are correctly identified as not having the condition being tested for; a test with high specificity has few false positives

**stem cell** a 'generic' cell that can make exact copies of itself indefinitely; in addition, such cells have the ability to produce specialised cells for various tissues in the body, including blood, heart muscle, brain and liver tissue; found in the bone marrow

**stress inoculation training** a form of stress-reducing intervention in which participants are taught to control stress by rehearsing prior to going into stressful situations; participants are taught to relax and use calming self-talk (he approach was developed by Donald Meichenbaum)

**stress management training** a generic term for interventions designed to teach participants how to cope with stress

**stress reactivity** the physiological arousal, such as increased heart rate or blood pressure, experienced during a potentially stressful encounter

**subjective expected utility (SEU) theory** a decision-making model where an individual evaluates the expected utility (cf. desirability) of certain actions and their outcomes and selects the action with the highest SEU

**subjective norm** a person's beliefs regarding whether important others (referents) would think that they should or should not carry out a particular action; an index of social pressure, weighted generally by the individual's motivation to comply with the wishes of others

**subjective** personal, i.e. what a person thinks and reports (e.g. excitement) as opposed to what is **objective**. Subjective is generally related to internal interpretations of events rather than observable features

**sympathetic nervous system** the part of the autonomic nervous system involved in mobilising energy to activate and maintain arousal (e.g. increased heart rate)

**synapse** junction between two neurons or between a neuron and target organ – nerve impulses cross a synapse through the action of neurotransmitters

**systolic blood pressure** the maximum pressure of blood on the artery walls, which occurs at the end of the left ventricle output/contraction (measured in relation to **diastolic blood pressure**)

## T

**T cell** a cell that recognises antigens on the surface of a virus-infected cell, binds to that cell and destroys it.

**tachycardia** high heart rate – usually defined as greater than 100 beats per minute

**telomeres** a compound found at the end of chromosomes that protect against DNA loss during cell replication and which need to be an optimal length to prevent this; short telomeres have been implicated in ageing

**temporomandibular disorder pain** a variety of conditions that cause tenderness and pain in the temporomandibular joint (hinge joint of the jaw)

**thalamus** area of the brain that links the basic functions of the hindbrain and midbrain with the higher centres of processing, the cerebral cortex; regulates attention and contributes to memory functions – the portion that enters the limbic system is involved in the experience of emotions

**theory** a general belief or beliefs about some aspect of the world we live in or those in it, which may or may not be supported by evidence – for example, women are worse drivers than men

**trait self-control** the general ability to resist temptation and suppress impulse

**transient ischaemic attacks** short periods of reduced blood flow to the brain resulting in symptoms including short periods of confusion, weakness and other minor neurological symptoms

**treadmill test** a test of cardiovascular fitness in which participants gradually increase the level of exercise on a treadmill while having their heart monitored with an electrocardiogram

**trigeminal neuralgia** a painful inflammation of the trigeminal nerve that causes sharp and severe facial pain

**type 1 diabetes** see **diabetes**

**type 2 diabetes** see **diabetes**

**Type A behaviour (TAB)** a constellation of characteristics, mannerisms and behaviour including competitiveness, time urgency, impatience, easily aroused hostility, rapid and vigorous speech patterns and expressive behaviour; extensively studied in relation to the aetiology of coronary heart disease, where hostility seems central

**Type C personality** a cluster of personality characteristics manifested in stoic, passive and non-emotionally expressive coping responses; thought to be associated with an elevated cancer risk

**Type D personality** a personality type characterised by high negative affectivity and social inhibition

## U

**ulcerative colitis** a chronic inflammatory disease of the large intestine, characterised by recurrent episodes of abdominal pain, fever and severe diarrhoea

**unrealistic optimism** also known as ‘optimistic bias’, whereby a person considers themselves as being less likely than comparable others to develop an illness or experience a negative event

## V

**variable** (noun): something that can be measured or is reported and recorded as data, such as age, mood, smoking frequency or physical functioning

**vasospasm** a situation in which the muscles of artery walls in the heart contract and relax rapidly, resulting in a reduction of the flow of blood through the artery

**visual field loss** loss of *part* of the usual field of vision. It does not involve blindness of either one eye or both

**volition** action or doing (the post-intentional stage highlighted in the HAPA model of health behaviour change)

**volitional** behaviour following deliberate or reflective processes rather than those which are automatic or impulsive

## W

**wellbeing** the subjective evaluation of a person’s overall life

**written emotional expression** a writing technique in which participants write about upsetting incidents either in their past or related to specific issues

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ISBN 978-1-292-26290-1

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