Chapter outline

Behaviour is linked to health, and as shown in the previous chapter 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 health-care professional. Although often used interchangeably, these terms are considered to suggest a

different relationship between a patient and a health-care 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 terms suggest that a person sticks to, or cooperates with, advice about medication (or lifestyle changes, behaviours) (NICE 2009a) in a more collaborative practitioner–patient relationship (diMatteo 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 a pharmacological or therapeutic literature to describe a jointly determined agreement between physician and patient as to what is the appropriate treatement, 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 health-care provider' (WHO 2009b).

Non-adherence behaviour, i.e. failing to follow recommended treatment or advice, can vary in extent, for example, from not filling 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 is 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). 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

(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 recent 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 recent randomised controlled trial amongst adults with Type 2 diabetes (Sutton et al. 2014) participants provided with electronic packaging which records the date and time of each opening of the container (a MEMS device) were modestly more adherent than those whose oral glucose lowering 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! Somewhat more recently (!) the WHO estimated that about a half of all medicines prescribed for chronic conditions are not taken as prescribed, and over all conditions, acute and chronic, about 25 per cent are non-adherent. However, adherence rates vary depending on many factors (di Matteo 2004a). DiMatteo's meta-analysis of data from 569 different study samples found some similarities across conditions; for example, adherence amongst those with cardiovascular disease averaged at 77 per cent, similar to the taking of essential immunosuppressant drugs amongst adult organ transplant patients, where 22.6 per cent were found to *not* adhere (Dew et al. 2007). However, variation was seen across many other conditions, 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 which we describe later in this section.

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, within the UK it has been estimated that individual non-adherence to prescribed medicines costs the UK NHS approximately £200 million *per year* due to repeat admissions to hospital, but a further £300 million may be wasted also due to not taking medicines as prescribed. This includes an estimated £90 million worth of unused and unwanted prescription medicines stored in individuals' homes, £110 million returned to pharmacies, and £50 million worth disposed within care homes (York Health Economics Consortium and University of London 2010). 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 they can be considered as falling into the following groupings (Sabaté 2003):

● *Patient-related factors*: e.g. culture, age, personality, knowledge, personal and cultural beliefs, attitudes

towards illness and medicines (see 'Research focus'), self-**efficacy** beliefs (see Chapter 5 👉).

- *Condition-related factors*: e.g. symptom type, perceived severity (NOT actual severity, diMatteo et al. 2007), presence or absence of pain, presence of comorbidities, prognosis.

- *Treatment-related factors*: e.g. the number, type, timing, frequency and duration of dosage of medications, presence and extent of side-effects, expense.

- *Socio-economic factors*: low educational level, costs of treatment (relates also to socio-economic equalities associated with ethnicity), access to dispensing pharmacy, social isolation.

- *System-related factors*: communications with healthcare provider regarding medicines, necessity or function, presence of traditional healing beliefs and systems (see 'Research focus').

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).

Influences on 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 age or 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. Few studies have in fact 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 health-care systems, transport systems, local economy) system influences were identified in qualitative interviews with 10 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 taken on an empty stomach which reduced 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 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

> **efficacy**
> Bandura's technical term analogous to confidence.

RESEARCH FOCUS

Concerns about medication and medication adherence in patients with chronic pain recruited from general practice

Rosser, B.A., McCracken, L.M., Velleman, S.C., Boichat, C. and Ecceston, C. (2011). *Pain*, 152: 1201-1205.

A range of factors explain or predict individuals' adherence to medicines, ranging from the personal and individual through to the cultural and socio-economic. This study addresses patient concerns about their medication for chronic non-malignant pain. Pain, as described in Chapter 16 (☛, is one of the main reasons a person goes to, or is referred to, a doctor. Quite commonly, no clearly defined pathology (see medically unexplained symptoms in Chapter 9 ☛) presents itself but nonetheless pharmacological medication is a mainstay of treatment, with psychological and behavioural interventions also offered in some cases. Medication typically involves painkillers (analgesics) of varying strengths and also non-steroidal anti-inflammatory drugs which help to reduce inflammation around joints (NSAIDs). As noted already, patient adherence, which is necessary if treatment effectiveness is to be reliably judged and amended if found not to be working effectively, is not always optimal. This paper examines patient concerns with the expectation that they hold the key to why medications are often used inappropriately or not at all.

Aims and methods

The study focused on primary care patients (instead of chronic patients in specialist care). A total of 239 patients (58 per cent female, 61.5 per cent married, almost 96 per cent white, age range 25 to 94 years old, with a mean of 61.46 years (and a wide standard deviation of 13.73)) were recruited which represented 36 per cent of those initially contacted, following identification by 20 different GPs across 10 practices in southwest England. Issues of sample bias are acknowledged and discussed in the paper.

Participants were assessed at one timepoint. In addition to reporting their pain (intensity rated from 0 (no pain) to 11 (worst pain possible)) and treatment history, they provided information about the dosage and frequency of their use of prescribed and non-prescribed medication. The authors' Pain Medication Attitudes Questionnaire (McCracken et al. 2006) assessed 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

The dependent variable was medication adherence (general adherence, underuse, overuse) using self-reports of general rather than specific medication use. This decision was primarily because of likely polypharmacy, i.e. chronic pain patients typically have varied and multiple medications and therefore assessing adherence only in terms of the patients' 'main' treatment would limit comparisons that could be drawn across the sample (e.g. some might respond in relation to paracetamol, others to morphine). Assessing general adherence therefore focuses on the populations' behaviour rather than the substance.

Underuse was assessed with regards to the frequency with which the individual (a) 'misses' a dose, and (b) 'takes less than prescribed'. Overuse was assessed in terms of the frequency with which the individual (a) takes an extra dose/s and (b) 'takes more than prescribed'. These four items were scored from 0=never, to 4=always, with a mean calculated for overuse and underuse separately, and total 'non-adherence' score computed from the score across all four items, described as 'general non-adherence'.

Participants also completed a checklist of 'side effects', consisting of 10 common adverse effects of painkilling analgesics, such as drowsiness, impaired concentration, agitation.

Results

Participant characteristics

Over a third of the sample were not working, worked part-time or had retired because of their pain, and 41.8 per cent were in receipt of state benefits. The median pain duration was 10 years (range 3-4 months to 50 years), and at the time of study 94 per cent judged their pain as chronic, 64 per cent saying it was constant. With a score of 11 referring to the 'worst pain imaginable', the mean present intensity was 5.2 (sd 2.5) with a slightly higher mean being 'usual' (6.1, sd 2.3). This suggests moderately high pain being experienced a lot of the time. Just over half of the sample (53 per cent) attributed their pain to osteoarthritis, and 37 per cent of the sample had had at least one pain-related surgery (e.g. likely joint replacements for those with osteoarthritis, i.e. hip or knee replacements).

Participant medications

Participants were in receipt of a modal N of two medications (this ranged from 1 to 21, suggesting a need for some outlier removal perhaps), with weak opioids being most common (67.4 per cent), (8.4 per cent were prescribed strong opioids), followed by NSAIDs (50.6 per cent), and then over-the-counter medications, mainly paracetamol (36.8 per cent). However, a significant minority (19.2 per cent) were in receipt of tricyclic antidepressants, a potentially important influence on results.

Adherence behaviour

Questions about adherence were asked in two ways, one very direct with a 'yes' or 'no' answer to 'do you take your medication exactly as prescribed?', the other more specific questions regarding over- or underuse. Interestingly these provide differing pictures. In response to the direct question, 75.6 per cent of participants answered 'yes', but subsequently 47.6 per cent report taking medication 'less than prescribed', 52 per cent 'miss a dose at least some of the

time, 23.4 per cent take 'more than prescribed' and 30.4 per cent 'take an extra dose at least some of the time'! This really illustrates the power of our questions to influence findings!

Overall, in this sample the average rate of general non-adherence was 38.4 per cent with almost a fifth of participants reporting instances of both over- and underuse – these behaviours are not therefore mutually exclusive.

Reasons for underuse included:

- low pain (31.8 per cent)
- forgetting (18.4 per cent)
- concern about side effects (13.4 per cent)
- worries about medication losing effectiveness (7 per cent)*
- worries about addiction or dependence (7 per cent)*.

(*These two reasons may be clinically meaningful, although not statistically so)

Reasons for overuse primarily included:

- having too much pain to tolerate (33.9 per cent)
- to help cope with a particular task (7.5 per cent).

Relating medication concerns to adherence patterns

Correlation analyses revealed a range of significant reasons for patterns of non-adherence as presented in the table below. Increased concerns about addiction were, unsurprisingly, reported by those who had some opioid-based medications.

In addition, frequency of side effects was positively and strongly associated with all the concern items, but ONLY to medication overuse. This finding is hard to disentangle in a cross-sectional study but by *controlling for* side effect frequency and reanalysing the association between adherence and medication concerns, overuse correlated only with perceived need for the medication, concerns about side effects, and concerns abut tolerance.

The final analyses conducted were multiple regression analyses, one for each adherence 'outcome'. It is unclear from the results described whether patient

Reason strength	Reasons for general non-adherence	Reasons for medication underuse	Reasons for medication overuse
Strong	Mistrust of doctor	Perceiving a low need for the medication Low concerns about withdrawal effects	Perceived need for the medication Concerns about side effects Concerns about tolerance
Moderate	Concerns about side effects Concerns about others' scrutiny	Mistrusting the doctor	Concerns about addiction Mistrust of doctor
Mild	Concerns about drug tolerance Concerns about addiction		Concerns about others' scrutiny

characteristics, (i.e. length of time living with pain, previous surgery, presence of current antidepression treatment and all sorts of other possible factors) were controlled for, although the level of pain was, however. The level of pain did not explain general non-adherence, nor overuse, although it was significant for underuse.

- 19.1 per cent of the variance in **general non-adherence** was explained by low concern over withdrawal, concern over side effects, and mistrust in the doctor.

- 19.6 per cent of the variance in **underuse** was explained by low level of pain, mistrust in doctor, and low concern over withdrawal.

- 18.9 per cent of the variance in **overuse** was explained by a high perceived need and concerns over side effects.

Discussion

What does this all mean? Certainly there are limitations to this study, including the relatively low response rate, the mixed sample in terms of pain and medication experience, and the fact that data is reported from one timepoint only. A strength, however, is that the study examines different forms of non-adherence, over- and underuse, and explicitly relates each to patient concerns. This is worthwhile when one looks at what emerges for each 'outcome'.

For example, mistrust of the prescribing doctor and reports of general non-adherence and underuse are important and need addressing through health professional communications training. Patient concerns

about side effect and general non-adherence echoes this need.

However, some of these findings are surprisingly counter-intuitive and warrant greater consideration: why would someone overuse a medicine when so many medication concerns are present? Does the perceived need for medication outweigh concerns? Overuse was NOT explained by high pain level, where underuse was explained by low pain. Overuse in the face of so many reasons for non-use seems to me, as the authors suggest, to be a different kind of phenomenon. Although not sufficiently developed by the authors, the results strongly suggest conflicted behaviour: patients who have many concerns about what they continue to take. It would be useful to explore this in terms of implication for patients' emotional well-being, especially when analyses also idenitified a significant association between overuse non-adherence and side effect frequency, which did not emerge for general non-adherence or underuse.

The authors conclude 'Patient concerns appear more pivotal in determining non-adherence than both level of pain and frequency of side effects experienced'. Whilst making an interesting contribution, what is equally pivotal will be exploring these questions longitudinally in a more homogeneous sample – only then can we begin to understand the overuse findings as highlighted: does overuse cause the concerns, or are the concerns ignored in the face of a great perceived need for treatment?

Once again, human behaviour is complex and there will not be a straightforward explanation!