HEALTH PSYCHOLOGY

5TH EDITION

THEORY, RESEARCH & PRACTICE

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SAGE

Los Angeles / London / New Delhi
Singapore / Washington DC / Melbourne
MEDICINE TAKING: ADHERENCE AND RESISTANCE

Drugs don’t work in patients who don’t take them.
Former US Surgeon, General C. Everett Koop

OUTLINE

Adherence and compliance are terms used to describe the extent to which patients adhere or comply with recommended treatment regimens. It is one of the most widely researched forms of health-related behaviour. The assumptions underlying the term ‘compliance’ implies an authoritarian stance on the part of the physician or other health professional that is challenged by recent changes within health care systems. This chapter considers the extent and character of treatment non-adherence and the issue of medical error. It also considers the patient-centred formulation of health care that focuses on shared decision-making and patient empowerment.

WHAT IS ADHERENCE?

CHARACTER OF ADHERENCE

The prescription of medicines is the most common form of medical treatment. Indeed, the terms for the profession and the form of treatment are interchangeable. However, a challenge faced by medicine is that most patients do not fully comply with the prescribed medication. This non-compliance can take various forms, including not having prescriptions filled, not taking the correct dosage, not taking the medicine at the correct times, and stopping the medication before the course of treatment is completed. This incomplete medicine taking has attracted a massive research effort and given rise to a range of competing claims.
The terms used to describe the process have changed over the years. Initially, the most popular descriptive term was **compliance**, which referred to the extent to which the patient passively accepted the physician’s instructions on medicine taking. With the growing challenge to the power of medicine, the term **adherence** has become more popular, because it is considered a more neutral expression. More recently, the term **concordance** has been introduced because it implies a more cooperative relationship between physician and patient. In this chapter, we will start with the popular term ‘adherence’ and then consider some more critical options.

In addition, there has been discussion about the use of the term ‘patient’ with its implications of passivity and acceptance. Frankenberg (1982), in his classic work on time in the health care setting, extends this discussion. He notes that in the traditional health care setting the patient is expected to be ‘patient’ and to ‘wait’ in the waiting room for the medical doctor. The longer the patient has to wait for an appointment is an indication of how important the medical doctor is. Indeed, the medical doctor can manipulate this arrangement. In their extensive review of research on adherence, Horne et al. (2005) noted that especially in the mental health context there is a preference for the term ‘service user’. However, there have been moves to reassert the role of the patient with patient rights groups and the introduction of the ‘expert patient’ into health decision-making. Within the research literature on medical adherence the preference is to use the term ‘patient’, although, as we will see, there is also discussion about patient empowerment – even a move towards the impatient.

Adherence to correctly prescribed medications is essential for good outcomes of patient care and properly controlled evaluation of different modes of drug treatment. Satisfactory adherence includes timely initiation of dosing plus punctual and persistent execution of the dosing regimen throughout the specified duration of treatment. Electronic methods for compiling drug dosing histories are now the recognized standard for quantifying adherence. Prior to electronic data collection, methods of assessing adherence consisted of counting returned, untaken doses, questionnaires, histories, diaries, assays of drug concentration in blood samples, and audits of prescription refills. Such methods ‘gave only fragmentary glimpses of an ambulatory patient’s dosing history, typically indicating that doses must have been omitted but at indeterminable times’ (Blaschke et al., 2012: 276). Thus, the frequency of inadequate adherence is probably underestimated by these pre-electronic methods and would generally be unnoticed as a cause of failed treatment or underestimated effectiveness.

Although there is extensive literature on adherence outside the medical setting, this literature is not discussed in this chapter. Further details can be found in the discussion of smoking cessation and exercise involvement.

### EXTENT OF ADHERENCE

The extent of adherence varies across the different forms of recommended medication-related behaviours. In general, most people do not adhere to specific medical or health care directives – at least not fully. While non-adherence would seem to be the norm, its extent varies. It has been estimated that 50–75% of patients do not adhere to medical advice (Wertheimer and Santella, 2003). Some further estimates include:

- 14–21% of patients do not fill their prescriptions;
- 60% of all patients cannot identify their own medication;
- 30–50% of all patients ignore or compromise medication instructions;
- 12–20% of patients take other people’s medication.
Recent evidence based on electronic recording of dosing has been reviewed by Blaschke et al. (2012). Their review suggests that only 55% of patients correctly adhered to their prescribed medication over a one-year period.

From a medical treatment perspective, this high rate of non-adherence reflects a major failure in the system. There have been attempts to document the negative impact of non-adherence. For example, Wertheimer and Santella (2003) estimated that each year in the USA:

- approximately 125,000 people with treatable ailments die of inappropriate medication usage;
- approximately one-quarter of nursing home admissions are due to inappropriate medication usage;
- hospital costs due to medication non-adherence were then $8.5 billion.

**Figure 19.1** *Taking Physick*, by James Gillray, 1800
Other researchers have calculated even higher costs. For example, Osterberg and Blaschke (2005) reported that 30–69% of medication-related hospital admissions in the USA were due to poor adherence and this amounted to additional health care costs of up to $100 billion.

Certain forms of non-adherence are potentially more dangerous than others. One common health problem that has a high rate of non-adherence is asthma. Despite the large number of drug education programmes, the proportion of people with asthma who do not comply with the recommended treatment remains high (Bender et al., 1997). In the USA, it has been estimated that the direct and indirect costs of asthma in 1990 were over $6 billion (Weiss et al., 1992). It has been suggested that a large proportion of this cost could be eliminated if adherence with medication was improved (Bender et al., 1997).

This low rate of adherence has attracted a massive research effort to identify what factors are associated with the process and how it can be enhanced. In an extensive review of the research literature, Vermeire et al. (2001) concluded there has been limited consistent success in identifying factors that predict adherence, due to a lack of concern with the patient’s perspective and a preference for quantitative methods. We will start by summarizing some of the evidence from the more quantitative research before considering alternative approaches.
A French study assessed demographic and psychological characteristics of patients with irritable bowel disease (IBD), many of whom were members of the French association for IBD sufferers (Nahon et al., 2011). Patients belonging to the French IBD patients’ association (AFA) were found to be more adherent to treatment than those who did not. The AFA helped patients to increase their knowledge about IBD and provided psychological support. Adherence to treatment was associated with psychological distress as measured by high anxiety scores on the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983), but not with high depression scores and not with socio-economic deprivation.

FACTORS ASSOCIATED WITH NON-ADHERENCE

PATIENT CHARACTERISTICS

There has been some success in identifying the social and personal characteristics of the non-adherent patient. In general, the less social support and the more socially isolated the patients are, the less likely they are to follow medical directives. For example, in a study of treatment adherence in an outpatient clinic for people with tuberculosis, it was found that homelessness was the only factor that predicted non-completion of therapy (Brainard et al., 1997). Further, individuals who came from unstable families were also found to be less compliant with medical treatment (Bender et al., 1997). A study of adherence among diabetes patients found that adherence to medication was associated with higher levels of social support (Gray-Sevilla et al., 1995).

There has been much effort to identify the so-called ‘non-compliant’ personality. However, like much personality research in general, this effort has met with limited success. In reviewing the evidence, Hulka (1979) found no consistent relationship between age, sex, marital status, education, number of people in the household, social class and adherence. Admittedly, this is not to deny that specific groups of patients may be resistant to accepting certain types of treatment. For example, certain cognitive deficits or emotional upsets may reduce adherence. There is also evidence that people with a range of psychological problems are less likely to adhere to treatment (e.g., Christianse et al., 1989; Stilley et al., 2004). Table 19.1 summarizes some of the patient characteristics associated with adherence.

It has been argued that the more the prescribed medication accords with the patients’ belief systems, the more likely they are to comply with the treatment. In an attempt to coordinate this research beyond the extensive listings of variables, some investigators have turned to the popular social cognition models. Probably the most frequently used such model has been the health belief model (HBM). Indeed, this model was originally formulated to explain compliance with medical recommendations (Becker and Mainman, 1975). According to the HBM, the extent to which a person complies or adheres with certain medication advice depends upon perceived disease severity, susceptibility to the disease, benefits of the treatment recommended and barriers to following the treatment (see also Chapter 8).

Varying degrees of support have been found for this model. For example, Masek (1982) found that the more the patients perceive their condition to be serious, the more likely they will be to comply with the recommended treatment. However, Glasgow et al. (1997) found that perceived seriousness of diabetes was not predictive of adherence. In a study of drug therapy defaulting, Fincham and Wertheimer (1985) found that belief in the benefits of medical care and low barriers to care predicted high adherence. Glasgow et al. (1997) found that the perceived effectiveness of the treatment was a better predictor of adherence in diabetes than the perceived barriers.
In a meta-analysis of 47 independent studies, Gonzalez et al. (2008) found a significant association between depression and treatment non-adherence in patients with diabetes. Studies that used stronger methodologies were found to have larger effects. Gonzalez et al. concluded that treatment non-adherence may be an important pathway between depression and worse diabetes clinical outcomes.

In a review of non-adherence in dialysis patients, Clark et al. (2014) suggested that it is difficult to compare the results from different studies because of the complex nature of non-adherence and the variety of methods and criteria that are employed. They suggested that large-scale, prospective studies are needed to investigate the association between psychological factors and non-adherence.

Various social cognition models have been used with varying degrees of success to explain non-adherence. Tillotson and Smith (1996) found that although internal locus of control predicted adherence to a weight-control programme for patients with diabetes, its importance was small and depended on the degree of social support. In a study of patients with rheumatoid arthritis, Beck et al. (1988) found that patients’ predictions concerning their adherence (self-efficacy expectations) with treatment predicted actual adherence. There has been a growing literature on adherence to HIV antiretroviral treatments. Some of these have found support for some of the social-cognitive dimensions. For example, a study in New York found that self-efficacy for adherence to HIV treatment significantly predicted adherence (Halkitis et al., 2005). However, this relationship may have been complicated by the role of recreational drugs that are common among individuals who are HIV positive and which, in turn, are associated with poorer adherence and also with avoidant coping. This led the authors to conclude that there is a need to consider the complex relationship between intrapsychic and socio-cultural realities in order to explain HIV treatment adherence.

Saal and Kagee (2011) considered the value of the theory of planned behaviour in explaining adherence to HIV/AIDs treatment. They found that attitudes towards adherence, perceived behavioural control and perceived group norms only explained 12% of the variance in intentions to adherence.

<table>
<thead>
<tr>
<th>Table 19.1 Patient characteristics associated with adherence</th>
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<tbody>
<tr>
<td><strong>Social characteristics</strong></td>
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<tr>
<td>Characteristics of individual’s social situation</td>
</tr>
<tr>
<td>Lack of social supports</td>
</tr>
<tr>
<td>Family instability or disharmony</td>
</tr>
<tr>
<td>Patient’s expectations and attitudes towards treatment</td>
</tr>
<tr>
<td>Residential instability</td>
</tr>
<tr>
<td>Environment that supports non-adherent behaviour</td>
</tr>
<tr>
<td>Competing or conflicting demands</td>
</tr>
<tr>
<td>Lack of resources</td>
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Source: Meichenbaum and Turk (1987: 43)
An approach to understanding adherence which has evolved from the common-sense model of illness is the Necessity-Concerns Framework (Horne, 2003). According to this framework, the extent of adherence depends upon a cognitive and emotional appraisal of the illness and of the role of medication in reducing the perceived threat. If people view their illness as threatening and the prescribed treatment to have more positive than negative consequences, they are more likely to adhere to the treatment. This approach has attracted considerable research, with the development of the Beliefs about Medicines Questionnaire (BMQ) (Horne et al., 1999). In addition, there is evidence that interventions based upon the common-sense model (CSM) of illness improve adherence (Jones et al., 2016).

The social cognition models of adherence describe the beliefs that are associated with or predict adherence. These models can be criticized on both empirical and theoretical grounds. On empirical grounds, the major problem is that the beliefs have been found to predict only a small proportion of the variance of adherence behaviour. Theoretically, the major problem is that these models reify the phenomenon. As such it characterizes the behaviour as fixed and abstracted from the changing social relations and the broader social context within which adherence occurs. Treatment is not usually a one-off event but extends over a period of time. In the case of chronic illness this period can be a lifetime. To understand adherence fully therefore requires an understanding of the social context and how the patient integrates the treatment into his/her everyday life. Literacy is also an important facilitating factor in adherence.

**DISEASE CHARACTERISTICS**

Certain disease characteristics have been found to be associated with adherence. Perhaps the most frequently mentioned disease characteristics are the severity of the disease and visibility of the symptoms. The relationship with disease severity would appear not to be linear. A number of studies have found that patients with asymptomatic chronic diseases frequently do not comply with treatment (e.g., Miller, 1997). When the symptoms are obvious and unwanted, the person is more likely to comply with treatment that offers a promise of removing them. However, when the prognosis is poor there is evidence that the rate of adherence is reduced. For example, Dolgin et al. (1986) found adherence lower in those cancer patients whose survival prospects were poor.

**TREATMENT FACTORS**

There is a large number of treatment factors associated with adherence. These are summarized in Table 19.2 under four broad temporal headings. Before the patient is actually prescribed a treatment, she/he has to obtain an appointment with the physician. The character of this process prepares or sets the scene for the physician’s recommendations. Lengthy or inconvenient waiting times can lead to considerable frustration and unwillingness to comply.

The more complicated the treatment prescribed, the less likely the patient is to comply fully. Admittedly, there have been attempts to simplify treatment regimens by providing patients with detailed information. However, the evidence suggests that adherence is still poor. One reason is information overload (Meichenbaum and Turk, 1987). In an attempt to cope with a very complicated treatment regimen the patient simply gets confused or ignores much of the information. Although physicians may explain the treatment, patients frequently forget or do not understand the instructions provided. Ley (1979) found that patients forget at least one-third of the information given by their physician. A variety of factors influences understanding. Basically, the more extensive and complex the instructions given, the less likely the patient is to recall it subsequently.
Besides complexity, an important treatment characteristic is the actual length of the treatment regimen. Adherence declines with an increase in the number of medications or doses and with the length of recommended treatment (Hulka et al., 1976). Sackett and Snow (1979) estimated that adherence with long-term therapy declines to approximately 50%, irrespective of illness or setting. Masur (1981) suggests that it is not the length of treatment that is the reason for this decline in adherence, but rather the absence of symptoms. Long-term therapy is often recommended for chronic medical conditions that have few symptoms or for which there is no definite improvement in symptoms as a result of medication. In these cases, the patient has no feedback on the benefits of medication. This lack of feedback undermines any motivation to comply with the medication. Leventhal (1986) found that when patients with hypertension were able to identify symptoms of their disease that were controlled by medication they were more likely to comply with it.

The actual character of the treatment is also important. For example, some people with asthma do not like taking inhaled medication while others do not follow the correct inhalation procedure, thus reducing overall adherence (McFadden, 1992). Understanding how the patient feels about a particular procedure or treatment is a necessary step in improving adherence.

It would perhaps be expected that those drugs with few physical side effects would be associated with higher adherence. It would seem that the social side effects, in terms of stigma, are just as important (see section on empowerment). A related factor is the extent to which the treatment disrupts the patient’s everyday life.

Table 19.2  Treatment factors associated with non-adherence

<table>
<thead>
<tr>
<th>Preparation for treatment</th>
<th>Immediate character of treatment</th>
<th>Administration of treatment</th>
<th>Consequences of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristics of treatment setting</td>
<td>Characteristics of treatment recommendations</td>
<td>Inadequate supervision by professionals</td>
<td>Medication side effects</td>
</tr>
<tr>
<td>Long waiting time</td>
<td>Complexity of treatment regimen</td>
<td>Absence of continuity of care</td>
<td>Social side effects</td>
</tr>
<tr>
<td>Long time elapsed between referral and appointment</td>
<td>Duration of treatment regimen</td>
<td>Failure of parents to supervise drug administration</td>
<td></td>
</tr>
<tr>
<td>Timing of referral</td>
<td>Degree of behavioural change</td>
<td>Inconvenience</td>
<td></td>
</tr>
<tr>
<td>Absence of individual appointment times</td>
<td></td>
<td></td>
<td>Expense</td>
</tr>
<tr>
<td>Lack of cohesiveness of treatment delivery systems</td>
<td></td>
<td></td>
<td>Characteristics of medicine</td>
</tr>
<tr>
<td>Inconvenience associated with operation of clinics</td>
<td></td>
<td></td>
<td>Inadequate labels</td>
</tr>
<tr>
<td>Poor reputation of treatment facility</td>
<td></td>
<td></td>
<td>Awkward container design</td>
</tr>
</tbody>
</table>

Source: Meichenbaum and Turk (1987: 43)
There has been considerable research on the extent of adherence to medical treatment among people with HIV. The treatment requires taking medication twice a day and missing no more than two doses a month. If this regime is not followed, there is the prospect of the development of drug resistance and more rapid disease progression. Parsons et al. (2007) conducted a study of adherence among HIV patients who were undergoing antiretroviral treatment. Using questionnaires, they examined the role of alcohol, affective factors (e.g., anxiety), cognitive factors (e.g., attitudes, self-efficacy) and social factors (e.g., social norms) in predicting the extent of adherence. They found that self-efficacy, which they defined as the belief in the ability to follow the treatment despite the medication, was the best predictor.

**INTERPERSONAL FACTORS**

The character of the physician–patient relationship has been at the centre of research into adherence. Physician styles in physician–patient communication have been classified as either ‘patient-centred’ or ‘authoritarian’ (see Chapter 14). The patient-centred or affiliative style is designed to promote a positive relationship and includes behaviours such as interest, friendliness and empathy. The authoritarian or control-oriented style is designed to maintain the physician’s control in the interaction. Not surprisingly, patients prefer those physicians who adopt the more affiliative style (Buller and Buller, 1987). Various related styles of physician interaction have been associated with adherence. In behavioural terms, the physician keeps good eye contact, smiles a lot and leans in towards the patient – all behaviours that are interpreted as demonstrating interest and consideration. Hall et al. (1988) found in their meta-analysis of 41 studies that patient satisfaction was associated with perceived interpersonal competence, social conversation and better communication as well as more information and technical competence.

Several studies have found an association between physician job satisfaction and aspects of adherence. McGlynn (1988) found that patients were more satisfied with those physicians who had high job satisfaction. A related factor is the physician’s sense of security. Since many conditions are resistant to standard medical interventions, many physicians can experience a sense of inadequacy. This, in turn, can lead to reduced job satisfaction and more conflict with patients. Indeed, when general practitioners receive complaints from their patients, they initially feel out of control and may experience feelings of shock, panic and indignation (Jain and Ogden, 1999).

Physicians and patients have a different view of health and illness. For example, St Claire et al. (1996) compared the definitions of health provided by a sample of family physicians and those provided by a sample of patients with asthma. Whereas the former defined health in terms of absence of disease, the latter referred to ‘being able’, ‘taking action’ and ‘physical well-being’. The more understanding the physician has of the patient’s belief system, the more compliant the patient is. For example, Ruiz and Ruiz (1983) found that Hispanic patients tend to comply more when their physician is more understanding of their cultural norms and practices.

An important, although less explored, factor is the physician’s view of the patient. This factor overlaps with the physician’s understanding of the patient’s health beliefs and suggests that when the physician has a positive view of the patient, she/he will adopt a much more affiliative style of communication. This helps to explain the well-established social class effect that upper and middle-class patients receive more information and attention from physicians. For example, Taira et al. (1997) conducted a large survey of state employees in Massachusetts. According to the responses, physicians were more likely to discuss healthy lifestyle issues such
as diet and exercise with high-income patients but they discussed smoking more with low-income patients. Physicians frequently report more frustration with and less interest in lower and working-class patients (Hall et al., 1988).

An interesting additional factor is the effect of a physician’s ‘tactile contact’ with the patient. In a recent study in France (Guéguen and Vion, 2009) a group of physicians were instructed to lightly touch their patients when giving advice on medication. It was found that compared with a control group of patients, the ‘touched’ patients were significantly more likely to consume more of the prescribed tablets. This effect was apparent seven days after the consultation. It was suggested that this effect may be due to those physicians who lightly touched their patients being perceived as more competent. However, in view of the potential misinterpretation of touch, there is a need to advise caution in applying these findings, particularly in societies where there are clear professional restrictions on tactile behaviour towards patients.

SOCIAL AND ORGANIZATIONAL SETTING

The medical consultation takes place in a social setting. Meichenbaum and Turk (1987) identified ten setting characteristics potentially associated with non-adherence. Adherence is greater when the referral to a specialist is seen as part of the assessment rather than as a last resort, when care involves follow-up and is personalized, when appointments are individualized and waiting times are reduced, when treatment is available on site, when treatment is carefully supervised through home visits, special nursing care, etc., when there are good links between inpatient and outpatient services, and when staff have a very positive attitude towards the treatment. In particular, with long-term therapy, there is evidence that regular follow-up by the physician increases adherence (Bond and Monson, 1984).

It is not just the immediate medical context but also the local social context, in terms of family and friends, which is important. If family members remind and assist the patient concerning their medication, it is only to be expected that the patient will be more compliant. Indeed, it has been suggested that the patient’s partner’s views of the medication prescribed is the most important factor in explaining adherence. In a meta-analysis of 122 studies on the impact of social support, DiMatteo (2004) found that practical support had a high correlation with adherence. He also found that adherence was higher in cohesive families and lower in families in conflict. This concern with social context requires consideration of the broader socio-political context that conditions the character of health care and of adherence.

In a review of the empirical research on factors contributing to reduced levels of adherence to medication, Osterberg and Blaschke (2005) developed a model of some of the key health care factors that are a barrier to adherence. This model identified three key processes:

1. Poor patient–provider communication (e.g., patient has poor understanding of the disease; patient has poor understanding of the benefits and risks of treatment).
2. Poor quality of patient interaction with the health care system (e.g., poor access to clinic appointments, poor treatment by staff, poor access to medication).
3. Poor physician interaction with the health care system (e.g., poor knowledge of drug costs, low level of job satisfaction).

There is an ongoing interaction between the patient, the provider and the health care system.
SOCIO-ECONOMIC STATUS

Less investigated is the importance of the person’s socio-economic circumstances. An initial attempt to connect environmental concerns with more psychological processes has been presented by August and Billimek (2016). This is summarized in Box 19.1. This figure shows that those individuals with low SES have limited resources to pay for certain medication. In addition, those resident in disadvantaged neighbourhoods are exposed to more environmental stress and a social norm which devalues medication adherence.

BOX 19.1

SOCIO-ECONOMIC STATUS, NEIGHBOURHOOD DEPRIVATION AND MEDICATION ADHERENCE

- Low individual socio-economic status
- Living in disadvantaged neighbourhood
- Lack of resources to pay out of pocket costs of medication
- Exposure to environmental stressors diminishes self-regulatory resources
- Social environment contributes to norms that devalue medication adherence
- Cost becomes a reason for non-adherence
- Unfavourable beliefs about medications become a reason for non-adherence
- Greater likelihood of medication non-adherence

Potential moderators:
Disease context, health-related social support/ control, health beliefs, self-efficacy, etc.

Source: August and Billimek (2016)

Cultural factors interact with socio-economic factors. For example, Villagran et al. (2011) found that the extent of adherence among Mexican immigrant patients depended upon the perceived power differential in the medical encounter as well as beliefs about complementary and alternative medicine.
ALTERNATIVES TO ADHERENCE

While the extensive quantitative literature on non-adherence has provided some insight into the character of the phenomenon, it has not contributed to its reduction (Vermiere et al., 2001). One of the main reasons for this lack of progress is that the majority of adherence research has been based upon a static model of the phenomenon that ignores the broader social context of health care and the dynamic nature of health and illness behaviour. An alternative, more social and psychological approach requires an understanding of the role of medicine in our society and of the actual lived experience of illness and of managing illness.

MODERN MEDICINE

In Western society, medicine has been based upon power and authority. Since it is founded on the assumption that it has the monopoly on truth, it follows that patient non-adherence is a result of ignorance and/or deviance. Thus it is not surprising that Trostle (1998: 1299) describes the literature on compliance as ‘a literature about power and control’. He argues that the increasing research interest in medical compliance is a reflection of ‘a concern for market control combined with a concern for therapeutic power’ (1998: 1301). However, this very concern with maintaining power may carry with it an equal and opposite reaction evidenced by a reluctance of patients to comply.

According to reactance theory (Brehm, 1966), individuals believe they have the right to control their own behaviour. When this right is threatened, they react and attempt to regain control over that behaviour and to prevent the loss of other freedoms. Basically, people do not like being pushed around and will attempt to subvert attempts to do so. In a revision of the original theory, Brehm and Brehm (1981) defined the concept of freedom as equivalent to that of control. People like to feel in control of their lives. Any attempt to reduce the sense of control over specific areas of our lives is a threat to the sense of freedom and is generally resisted.

The theory of psychological reactance has been used as an explanatory framework for non-compliance. The more extensive and complex the treatment prescribed, the greater the threat to perceived freedom (Fogarty, 1997). Admittedly, this threat would be accepted if there was an indication that it was worthwhile. However, the very complexity of some regimens may sensitize the patient to additional threats to their freedom such that patients may become resistant to additional demands. Non-compliance can thus be interpreted as a means of resisting medical dominance.

Admittedly, not all patients are critical of the traditional authoritarian stance of the physician or feel the need to resist or not comply. Some people are more accepting of authority than others. In recent years there has been more public opposition to the idea of the all-powerful doctor, and demands for greater control over health care. Despite this apparent change in public attitudes, several researchers have found that many people are reluctant to adopt a more resisting, consumerist attitude. Haug and Lavin (1983) found that while younger and more educated patients are more consumerist in their attitude regarding their role in the doctor–patient encounter, older patients are more accepting and accommodating.

Lupton (1997) investigated the impact of the supposed cultural shift on the attitudes of patients in Australia. She argued that contemporary popular advice is that the patient should adopt an active consumerist attitude to health care. In her interviews with a sample of patients, Lupton found a more mixed picture. Many of the patients, especially the older ones, still preferred the
passive patient role. Admittedly, they accepted that the traditional authoritarian image of the doctor had been challenged over the past generation as a result of publicity about medical negligence and sexual harassment. This resulted in ambivalence about the doctor and a tension between adopting the consumerist or passive patient role. Thus, while some patients would demand a more active role in their treatment and would be frustrated if they were denied it, many patients still preferred to adopt the traditional passive patient role.

The more consumerist stance of certain patients is not always welcomed by physicians. Although several studies have shown that patients generally express a desire for information about their condition, many physicians are reluctant to disclose much information. In his study, West (1984) found that physicians often ignored patients’ requests for information. Indeed, it was found that patients’ requests for more information were often met by challenges to their intelligence.

**ROLE OF THE PHYSICIAN**

Trostle (1998: 1303) suggested that ‘the last decade’s preoccupation with adherence is a consequence of the declining authority of the [medical] profession’. In traditional non-Western societies, the physician maintains the dominant role and the patient is more inclined to adopt a compliant stance. For example, Matsumoto et al. (1995) found that first-generation Japanese-Americans were much more likely to report a willingness to comply than their second-generation peers. Conversely, in Western society the demand for greater control over one’s life conflicts with the traditional passive role and leads to greater resistance to medical advice.

Another feature of medical dominance is the power of the physician to define sickness. It is often assumed that the doctor typically makes the correct diagnosis and prescribes appropriate treatment. This is the ideal medical model. This non-adherence is the patient’s fault. However, the evidence suggests that there are many sources of error on the part of the physician. For example, patients frequently attend with a variety of psychosocial problems, but physicians often ignore these. Bertakis et al. (1991) estimated that as many as 85% of patients who come to see their family doctor have some degree of psychological distress. As Mishler (1994) has emphasized, scientific medical discourse does not contain language to handle these issues so the physician prefers to focus concern on biomedical matters that may be of limited concern to the patient.

In a large study conducted over 11 sites in the USA, Bertakis et al. (1991) analysed the verbal content of 550 physician–patient interviews. They found that physician questions about biomedical topics were negatively related to patient satisfaction, whereas physician questions about psychosocial topics were positively associated with patient satisfaction. In addition, those patients whose physician dominated the interview reported less satisfaction.

However, Waitzkin (1989: 232) argues that the exclusion of discussion of the social context of health complaints is a ‘fundamental feature of medical language … a basic part of what medicine is in our society’. Not only does medical language ignore these social issues, but also medical treatment does not address these social issues. He suggests a redirection for medicine: ‘By suggesting collective action as a meaningful option, medical professionals might begin to overcome the impact that its exclusion exerts.’ To do this it needs to recognize the ‘limits of medicine’s role and the importance of building links to other forms of praxis that seek to change the social context of medical encounters’ (Waitzkin, 1989: 237).
The movement towards patient-centred models of medical treatment indicates that the medical profession is well aware of the growing criticism. So too are pharmacists, who play a central role in dispensing medication. A report by the Royal Pharmaceutical Society of Great Britain (1997) called for a new approach to patient care. In a commentary on the report, Marinker (1997: 7082) noted that ‘compliance may have been appropriate within a welfare state rooted in the values and thinking of society in the 1930s, when services were driven by benign paternalism and the practice of patients trusting their doctors’. The alternative that the report proposed was concordance, which is a model of the doctor–patient relationship based upon mutual respect (Vermeire et al., 2001). Marinker (1997: 7082) concluded: ‘The price of compliance was dependency – it belongs to an older world. The price of concordance will be greater responsibility’ (for both the doctor and the patient). While this vision of shared responsibility seems commendable, as we shall discuss subsequently, it also holds the potential of medical neglect.

Overall, there is much evidence to suggest that non-adherence is an integral component of the contemporary medical-dominated health care system. To reduce non-adherence thus requires a reassessment of this system. It also requires an understanding of what it means to the patient to be ill.

LIVED EXPERIENCE OF CHRONIC ILLNESS

The extent to which people, especially those with chronic illness, comply with recommended treatment is enmeshed in their experience of living with illness. Adherence is not a fixed event but a changing process. An increasing number of qualitative studies of illness help us to understand the processes by which people make sense of the prescribed treatment regimens. Some of these processes are considered here.

SELF-REGULATION

Individuals with chronic illness actively monitor and adjust their medication on an ongoing basis. It is not that they are recklessly ignoring professional advice, but rather they are carefully regulating it according to a variety of factors. This is illustrated in the study conducted by Conrad (1985). Over a three-year period, he conducted interviews with 80 individuals who had epilepsy about their life experiences with the disease. He noted that the individuals developed a personal ‘medication practice’ that best fitted with their self-image and their lifestyle.

The patients realized the benefits of medication for seizure control and frequently stated that the medication helped them be more ‘normal’. However, simultaneously the medication was seen as a daily reminder that they had epilepsy. They felt that reducing the medication was evidence that they were ‘getting better’. Side effects were a frequently given justification for not complying with the recommended treatment. However, although side effects were mentioned, they rarely referred to bodily side effects. Rather, they referred to social side effects. If the people with epilepsy felt that the medication was impairing their ability to handle routine social activities, they modified the medication to reduce this impact.

Box 19.2 summarizes four reasons that Conrad suggested underlie individuals’ preference to self-regulate the treatment rather than comply fully with the recommended regimen. These illustrate how non-adherence is a rational process whereby the individual carefully adjusts the medication to maximize its impact.

People carefully monitor the impact of prescribed medication and adjust the dosage accordingly. They do not simply follow the standardized instructions provided by the physician, but
rather adjust them to suit their own personal needs. This is illustrated in a study by Hunter et al. (1997), who looked at middle-aged women’s usage of hormone replacement therapy (HRT). They interviewed 45 women and identified three broad themes within which the women talked about HRT:

1. **Hot flushes and night sweats**: the women would not take the medication when there were no symptoms, e.g., one woman said: ‘I have no extraordinary symptoms, therefore I have no need of HRT’ (1997: 1544).

2. **Doctors’ opinions and behaviour**: the women listened carefully to their doctor’s advice and decided whether or not to take HRT, e.g., one woman said: ‘I came to the doctor and had a discussion. I felt that I weighed up the advantages and disadvantages’ (1997: 1544).

3. **Taking hormones or medication for a ‘natural’ process**: the women were reluctant to take medication for something that they felt was natural. They sometimes referred to a similar concern with taking the contraceptive pill, e.g., ‘I might consider it if I was suffering from symptoms which I felt I could not put up with. I’m a bit wary. I never really wanted to go on the pill because I’m always a bit wary of interfering with nature’ (1997: 1545).

This study illustrates that the patient’s attitude to the recommended treatment is interwoven with their attitude to the illness and their attitude to their physician.

The **self-regulatory model** of illness developed by Leventhal and Cameron (1987) provides a framework to explore patients’ medication beliefs. This model considers health-related decisions as dynamic rather than static. According to the model, whether a person adopts a certain coping procedure (e.g., adherence with medication) depends upon perception of illness threat and the perceived efficacy of the coping strategy. According to the model, concrete symptom experience is important both in formulating representations of the disease and in monitoring medication efficacy. Thus, a perceived lack of evidence of the disease or of the efficacy of the medication would encourage non-adherence. For Leventhal, the patient can best be considered as an active problem-solver.
An extension of this approach was developed by Horne and Weinman (1999). They developed a measure of medication beliefs that distinguished between the perceived benefits and harms of the medication. They found that patients’ beliefs about the efficacy and necessity of medication were tempered by concerns about the potential for harm. A study of patients with chronic illness found that there was a strong relationship between perceived necessity of the medication and reported adherence to the treatment (Horne and Weinman, 1999). In a recent extension of this work with individuals who had asthma, it was found that there was a relationship between illness perceptions (see Chapter 15), medication beliefs and adherence (Horne and Weinman, 2002). Those individuals with strong medication necessity beliefs also perceived asthma as having a lengthy timeline and that its consequences were serious. A statistical model found that treatment concerns and necessity and illness consequences were significant predictors of reported medication adherence.

A study using the Beliefs about Medicines Questionnaire (BMQ; Horne et al., 1999) found further supporting evidence of the importance of the patients’ medication beliefs. The study considered medication adherence among individuals suffering from chronic arthritis (Treharne et al., 2004). It found that those who perceived their medications as being more necessary and those who perceived medications as not being overused were more adherent to the prescribed medication.

Similar findings were found in a study of non-pharmacological treatment for dizziness (Yardley et al., 2001). In this study, patients were interviewed about the treatment. It was found that those patients who did not adhere to the recommended treatment attributed their symptoms to causes inconsistent with the rationale for the therapy. However, some other patients who did adhere also attributed inconsistent causes but emphasized trust in their physician or a willingness to try anything that might help. These patients reported an improvement in symptoms during the treatment period although they were hesitant about attributing the cause of this to the treatment. Yardley et al. concluded that while this study provided some evidence for Leventhal’s illness regulation model, there were also inconsistencies. It was suggested that these might be explained by considering the role of the therapist. These findings highlight the interaction between the ‘material’ (i.e., concrete, embodied) and the discursive (i.e., symbolic, socio-culturally mediated) aspects of health care (Yardley, 1997). Together, these findings would extend the illness regulation model to include the discursive and social context within which the illness and the treatment are situated.

Finally, a recent study of adherence to complementary therapies developed a dynamic extended model of treatment and illness representations (Bishop et al., 2008). This model conceives the patient as being involved in an ongoing review of the treatment to assess its effectiveness and the value of continued treatment. Using this model to test adherence to complementary therapies, it was found that positive perceptions of one’s therapist as well as a belief that the illness was not caused by mental factors predicted adherence to appointments. In addition, beliefs about the value of holistic health and difficulty attending appointments predicted adherence to the remedies prescribed.

**FEAR OF MEDICATION**

From the physician’s perspective, non-adherence can seem a foolhardy process. However, to the layperson, non-adherence can be perceived as a means of reducing a variety of fears. This is illustrated in the findings of a study conducted by Donovan and Blake (1992). They investigated
the extent to which a sample of people with various forms of arthritis complied with the recommended treatment. The study involved interviews and observations of 44 patients over a period of several years. They found that about half the patients did not follow the prescribed treatment. Detailed questioning of these patients revealed that they were carefully considering the implications of this non-adherence. It was not just a matter of obeying instructions or not – they were experimenting with dosages and timing. They were reluctant to follow the prescribed treatment for these reasons:

- fear of side effects;
- fear of dependency;
- fear of reduced effectiveness;
- did not fit with lifestyle;
- drugs as a sign of weakness;
- drugs do not fit with health beliefs.

Similarly, Britten (1994), in her study of lay people’s perceptions of medicines, found that many people have a range of fears and anxieties about medication. This was especially the case among those people who reported that they often did not comply with prescribed medication. In her discussion, Britten comments on the physicians’ urge to prescribe and suggests they should consider other options than medication.

In the development of the Beliefs about Medicines Questionnaire, Horne et al. (1997) distinguished between ‘general overuse’ (beliefs that medicines in general are over-used by doctors) and ‘general harm’ (beliefs that medicines in general are harmful addictive poisons). These two beliefs were found to be closely related. Subsequent work found that in a sample of British students, males, those with less experience of medication and those from an Asian background, had a stronger belief in the general harm of medicines (Horne et al., 2004). This would indicate that medication beliefs are closely intertwined with gender and cultural identity and with experience of medication.

IDENTITY CONTROL

Medication adherence is also tied to the extent to which the patient accepts that she/he has an illness and wishes to control it. This is illustrated in the study by Adams et al. (1997). They conducted detailed interviews with a sample of asthma sufferers registered with a general practice in South Wales. Analysis of these interviews revealed that the extent to which the individuals complied with the recommended treatment (daily use of a curative and a prophylactic inhaler) was intimately bound up with how they defined themselves and their attitude to the illness. Three groups of patients, each with a particular pattern of medication, were identified:

1. Deniers/distancers: these were the individuals who argued that despite the medical diagnosis they did not have asthma but rather just ‘bad chests’. They would fall into Goffman’s (1963) ‘discreditable’ category and took steps to ensure that others were not aware of their diagnosis. They generally had a negative view of people with asthma
(e.g., ‘weakling’ or ‘wimp’) and wished to avoid such a label. Although they took reliever medication when necessary, they were reluctant to take prophylactic medication regularly. While the former helped their ‘bad chest’, the latter was a symbol that they were ‘asthmatic’.

2. **Accepters**: these individuals reluctantly accepted that they had asthma. They also held a variety of negative associations of people with asthma. They emphasized that they were not stereotypical asthmatic people but rather more like certain individuals who were able to achieve despite having asthma, e.g., certain athletes. They defined asthma as a ‘condition’ that needed to be controlled. As such they not only took the reliever medication but also the prophylactic medication. However, these individuals emphasized that although they took their medication regularly, they were not dependent on their doctor. Rather, they were proud that they controlled their asthma themselves, using the drugs, with limited contact with their physician.

3. **Pragmatists**: these individuals did not fall neatly into the previous two categories, although they were closer to the accepters. All of them accepted that they had asthma but their notions of asthma and medication usage were somewhat idiosyncratic. Unlike the secrecy of the deniers and the public stance of the accepters, this group adopted a more pragmatic attitude and practised what Adams et al. described as a strategic policy of disclosure. This was related to their self-medication practices, to which they adopted a pragmatic stance.

**MEANING OF ILLNESS**

Within the phenomenological and narrative literature there has been substantial discussion on the role of perceived meaning. For example, within narrative psychology it has been argued that the creation of a narrative account helps bring order and meaning to events that are confusing (Murray, 2007; see Chapter 14). There is a substantial research literature on the perceived meaning of illness. In a study of published accounts of breast cancer, it was shown that many women search for meaning in their disease (Murray, 2009). It has been argued that greater narrative coherence is associated with feelings of well-being (Baerger and McAdams, 1999). It is possible that it is also linked to treatment adherence.

Recent research on writing has suggested that the process of writing can provide an opportunity for people to clarify the meaning of events in their lives. In a study by Westland et al. (2007), women with HIV were asked to participate in a regular writing task over one month. Analysis of what they had written found that those women who, during the writing task, had found some personal meaning in having HIV were more likely to have greater adherence to the medication prescribed at the end of the project. In this case, discovery of meaning was defined as ‘a major shift in values, priorities, or perspectives’. There is ongoing discussion about what is going on in such writing activities (Nicholls, 2007). The growth of creative writing classes in health care settings provides an opportunity for further research.

**RESISTANCE TO MEDICINE TAKING**

A common feature in qualitative research into medicine taking is the active role of the patient in assessing the value of the prescribed medication and deciding to what extent they should
accept or resist it. In an extensive review of the qualitative research, Pound et al. (2005: 149) concluded that ‘the urge to evaluate suggests widespread caution about taking medicines as well as distrust in the information given about medicines’. They developed a model of medicine taking that highlighted the active role of the patient in decision-making. Figure 19.4 shows that people will resist medication for a variety of reasons, especially concern about adverse drug reactions. They conclude that if the term ‘resistance’ sounds strong, ‘It should be remembered that the huge literature on “non-compliance” only exists because so many people have continued to resist taking medicines in the face of sustained advice, interventions and admonishments’ (Pound et al., 2005: 152).

**Figure 19.4  Model of medicine taking**

*Source: Pound et al. (2005: 139)*

**SOCIAL SETTING**

These studies illustrate that the extent of adherence with the recommended treatment is intertwined not only with the character of the disease, but also with the patient’s self-definition.
and the perceived meaning of the illness. Adherence or non-adherence is a means not only of managing symptoms, but also of managing self-identity. The patient does not simply follow the advice of the physician, but rather acts depending upon how she/he interprets it. However, these processes take place in a particular social setting. This setting can range from the immediate family setting to the broader societal setting.

Consider the case of juvenile diabetes. It is established that parents assume the responsibility for ensuring their child follows the treatment regimen, but as the child enters adolescence they transfer responsibility across. However, it is known that adherence to diabetes treatment begins to decline in adolescence (Miller and Drotar, 2007). The reasons for this decline include lack of parental involvement (Nansel et al., 2009) and lack of self-management skills (Modi et al., 2012).

An opportunity to ensure the transfer of self-management skills would seem to enhance adherence among adolescents with diabetes. Evidence to support this was found in a study by Miller and Jawad (2014), who found that those parents who reported that their youth expressed opinions and information during discussion about the illness management were more likely to report that their youth adhered to the treatment. Thus a family setting which encouraged and also facilitated self-management would be one in which the young people developed a sense of themselves as being responsible for the management of their illness.

Adherence can also be located in the broader socio-political setting. An example of this is given in Box 19.3.

**INTERNATIONAL CASE STUDY: THERAPEUTIC CITIZENS – THEORIZING BEYOND THE INDIVIDUAL**

The importance of broader political and historical context in explaining treatment adherence for HIV/AIDS is detailed in this collection of studies from Africa. Nguyen (2004) has developed the concept of the therapeutic citizen to describe the extent to which people actively participate as social and political beings in the use of medications. This concept has been taken up by Kagee et al. (2014) to explore the changing adherence to antiretroviral treatment for HIV/AIDS in South Africa over the past ten years. They begin by drawing attention to a range of more immediate structural barriers to adherence, including poor transport, food insecurity, over-burdened health care facilities, limited access to mental health services and difficulty accessing adequate counselling (Kagee et al., 2007; Kagee and Delport, 2010).

Kagee et al. (2014) refer to the period around 2008 when the political leadership in South Africa accused ‘white’ science as colluding with the ideas of apartheid. The government refused to make antiretrovirals (ARVs) available in the public health system since it was argued that AIDS was not caused by HIV but by poverty. This contributed to AIDS denialism.
(see Chapter 23). This in turn meant that the ART (Antiretroviral treatment) users were located in opposition to the state. As Kagee et al. (2014: 106) state: 'Part of that political identity was the daily action of being adherent to ART. Medication taking during this historical period was not only a health-promoting behaviour at the time but also an overtly political act.'

However, due to overwhelming pressure from AIDS activists and others, this AIDS denialism was rejected and now ART is widely available such that it has become more of a personal rather than a political act. Instead, adherence is presented as a pro-social act that is aimed at promoting the common good.

The current political context of lack of political direction and limited sign in improvement in the lives of people has created a new therapeutic context within which ART is located. Kagee et al. (2014: 107–8) conclude that ‘without a sense of a viable future, it may be more difficult to adhere to the demands of an ARV regimen, which in the short term may offer no benefits at all and is associated with inconvenience, stigma and side effects’.

Together these studies highlight the importance of moving from a personal to a political perspective to understand the changing use of certain medications.

Source: Nguyen (2004); Kagee et al. (2014)

**PHARMACEUTICAL INDUSTRY**

The elephant in the room in all discussion of medication adherence is the pharmaceutical industry (Big Pharma). This industry is one of the largest and most powerful industries in the world. It is dedicated to maximizing its profits through the promotion and sales of all forms of medication. Moynihan et al. (2002) describe their business as ‘selling sickness’. They go further to argue:

> Some forms of medicalizing ordinary life may now be better described as disease mongering: widening the boundaries of treatable illness in order to expand markets for those who sell and deliver treatments. … The social construction of illness is now being replaced by the corporate construction of disease. (Moynihan et al., 2002: 886)

The drug industry expends massive resources not just in developing new drugs, many of which are little different from other drugs, but in marketing these drugs to both the lay public and professionals. They do this through both direct and indirect marketing campaigns. In the process of medicalizing human health and personal problems, they promote drugs as being the only method of promoting health. Those approaches which characterize many such problems as being benign or self-limiting are rejected as being insufficient and instead both patients and health professionals are convinced that medication is necessary.

Gøtzsche (2013) has detailed the multiple legal and illegal methods that Big Pharma uses to promote sales. He compares their methods to that of the Mafia or the Mob. Further, he argues that the industry has corrupted science by its promotion of the limited benefits of many drugs. He details how the drug companies exert massive influence in the direction of research.
There have been many editorials in medical journals condemning the nefarious influence of drug companies but governments have only taken limited steps to control them. As Davis and Abraham (2013: 755) state: ‘Such timid regulatory behaviour may be symptomatic of the extent to which regulators have been encouraged by governments to be responsive to the commercial interests of industry and to view large drug firms as clients whose fees increasingly fund these agencies.’

With such widespread promotion of drugs worldwide it is not surprising that medication use is so widespread. According to the most recent Health Survey for England – 2013 (Health and Social Care Information Centre, 2014), 43% of men and 50% of women reported that they had taken at least one prescribed medicine in the last week. Even more alarmingly, 22% of men and 24% of women reported that they had taken at least three prescribed medicines in the last week. Among older people these figures were even higher with more than 70% of those aged 75 and over having taken at least three prescribed medicines. While many drugs have a beneficial impact on health, others have little impact or, of increasing concern, a negative impact.

**MEDICAL ERROR**

The desire of patients to evaluate the impact of the medication prescribed on their health is supported by the evidence on the extent of medical error. The term iatrogenesis was developed by Ivan Illich (1976) to describe health problems that are caused by medicine. While this term applies to the overall negative effects of the medical system, a particular issue is the extent of preventable medical error. Over the past 15 years there has been increasing awareness of the extent of medical error. In 2000 the US Institute of Medicine (IOM) published a report summarizing the growing evidence on the risk to the health of patients due to medical error (Institute of Medicine, 2000). This report highlighted two studies – one in Colorado and Utah and the other one in New York (Brennan et al., 1991) – that found that adverse events occurred in 2.9% and 3.7% of hospitalizations, respectively. Extrapolating to the whole of the USA, the report estimated that 44,000–98,000 Americans die each year as a result of medical error. That is more than die each year from motor vehicle accidents, breast cancer or AIDS.

Since the publication of the IOM report, other countries have produced similar reports. For example, in 2001 the UK Chief Medical Officer produced a report entitled *An Organisation with a Memory* (Department of Health, 2000a) and a subsequent action report detailing specific recommendations (Department of Health, 2001). This was followed by a report by the UK Chief Pharmaceutical Officer (Smith, 2004). These reports also referred to the high rate of adverse medical events. They highlighted one British study (Vincent et al., 2001) that found that 10% of patients admitted to two London teaching hospitals had experienced an adverse event, of which half were preventable. It was estimated that such adverse events generated up to £2 billion in additional costs to the NHS (Department of Health, 2000). A survey conducted by the Health Foundation (2004) in the UK estimated that as many as 40,000 deaths a year were due to medical error.

Smith (2004) estimated that 10–20% of adverse medical events are due to medication errors. In a study of 550,000 prescriptions written by GPs in Britain, pharmacists identified and averted 54 potentially harmful cases (0.01%) (Greene, 1995). However, a large proportion of errors go undetected or unreported. For this reason, Smith proposed a medication error iceberg to describe the situation. At the tip of the iceberg were those errors that cause actual damage and
are reported. But then there are the unreported errors that include errors identified with potential to cause harm (near-misses), errors identified but considered insignificant, potential errors and unnoticed actual errors. Together, this indicates that the extent of the problem is much greater than appears from the initial figures.

EXPLANATIONS FOR MEDICAL ERROR

Explanations of medical error frequently distinguish between the person and systems approaches (Reason, 2000). The person approach focuses on the individual and leads to the so-called ‘name, blame and shame’ approach to error management. The alternative systems approach considers the broader context with which errors occur. It emphasizes the importance of organizational change in order to reduce the risk of error. A summary of the person and systems explanations of medical error is provided in Figure 19.5.

In hospitals, it is junior physicians who do most of the prescribing. They are the ones with least knowledge and also the ones who make the most prescribing errors (Lesar et al., 1997). Wu et al. (1991) surveyed junior hospital physicians in internal medicine training programmes. They found that 45% reported making at least one error, 31% of which resulted in a patient’s death.

Weingrad et al. (2000), in their review of medical error, identified a series of potential risk factors. These included:

- age of patient – older patients are more at risk;
- type of intervention – certain types of surgery are particularly risky;
- emergency room usage;
- lengthy medical care;
- intensive medical care.

They concluded: ‘Unless we make substantial changes to the organization and delivery of medical care, all patients – particularly the most vulnerable – will continue to bear the burden of medical error’ (Weingrad et al., 2000: 776).

An important factor overall is the character of the physician–patient relationship. A survey of American physicians and members of the general public (Blendon et al., 2002) found that they agreed on two possible causes of medical error: shortage of nurses (53% physicians versus 65% of the public) and overwork, stress and fatigue of health providers (50% versus 70%). In addition, 72% of the public referred to too little time with their physician and 67% referred to health care professionals not working as a team or not communicating.

In a national survey of residents (junior hospital doctors) in the Netherlands (a sample of over 2,000 with 41% response rate), it was found that 94% reported that they had made one or more mistakes that did not have negative consequences for the patient. However, more than half (56%) reported that they had made at least one mistake that had a negative consequence for the patient (Prins et al., 2009). The strongest predictors of self-reported errors were emotional exhaustion and depersonalization. In addition, burnout was more predictive of perceived errors due to lack of time than errors due to judgement/inexperience. They concluded that there was a need for greater supervision and emotional support for junior doctors.
MEDICAL SILENCE

One common problem raised by all of the recent reports has been that of medical silence: the reluctance of health professionals, in particular physicians, to report errors. In a survey of physicians conducted in five countries (Australia, New Zealand, Canada, the USA and the UK) a large proportion reported that they felt discouraged from reporting or that they were not encouraged to report (Blendon et al., 2001). The proportion was over 60% in Australia and about 30% in the UK. This contrasts with the large proportion of patients and the general public who would prefer reporting of medical errors (Gallagher et al., 2003).

The Department of Health (2000) identified several reasons for this reluctance to report on the part of medical personnel. These included:

- lack of awareness that an error has occurred;
- lack of awareness of the need to report, what to report and why;
- perception that the patient is unharmed by the error;
- fear of disciplinary action or litigation, for self or colleagues;

Figure 19.5  Person and systems approaches to medication error

Source: Smith, 2004
lack of familiarity with reporting mechanisms;
- loss of self-esteem;
- staff feeling they are too busy to report;
- lack of feedback when errors are reported.

The Institute of Medicine report (Kohn, Corrigan & Donaldson, 2010: 3) expressed alarm that despite the high rate of error, ‘silence surrounds this issue. For the most part, consumers believe they are protected.’ It continued:

The goal of this report is to break this cycle of inaction. The status quo is not acceptable and cannot be tolerated any longer. Despite the cost pressures, liability constraints, resistance to change and other seemingly insurmountable barriers, it is simply not acceptable for patients to be harmed by the same health care system that is supposed to offer healing and comfort. (1999: 3)

This reluctance on the part of physicians to report has led to the establishment of mandatory reporting systems in many countries.

However, the reluctance of the physician to report also reflects their power and status in society and the reticence of the public and the patient to question medical authority. Whistle-blowers have often suffered stigma and discrimination, and sometimes unemployment, as a consequence of speaking out. Thus, implicit within any model to reduce medical error and to improve patient safety is the challenge of increasing public and patient involvement in the quality control of health care.

PATIENT EMPOWERMENT

Rather than attempting to control the patient – an approach that is implicit within models of compliance – empowerment attempts to increase patient autonomy and self-control. The empowerment approach is derived from the work of community educators and psychologists and is defined as the process whereby ‘people gain mastery over their lives’ (Rappaport, 1987: 3). Instead of imposing the views of the expert health professional, empowerment seeks to enhance the patients’ self-understanding and the potential of self-care (Feste and Anderson, 1995).

The focus of this approach is the enhancement of the strengths and potential of the patient. Through dialogue the health professional seeks to understand the needs of the patient. Skelton (1997) suggests that the aim of patient education within this model is to ‘blur’ the boundaries between professional-as-teacher and patient-as-learner. Instead of the professional’s health knowledge being considered paramount, the patient’s lay health beliefs and knowledge are considered of equal or greater value. A central component of this understanding is the opportunity for patients to tell their stories. In describing this process, Hunter (1991: 139) notes that ‘medicine has the power not only to rewrite the patient’s story of illness but also to replot its course’. Dependent upon the story that is handed back the patient will assess its relevance to their lives. As Hunter (1991: 142) continues: ‘If the two are widely disparate and the physician fails to recognize the distance between them, the interaction founders. The medicine will go untaken, the consultation unsought, the prescription unfilled.’
DESIRE FOR CONTROL

Patient empowerment can aim to involve the patient more in health care through attention to patient needs or it can increase the patients’ awareness of the broader social and political factors that adversely affect their health status. Admittedly, as Lupton (1997) found, not all patients wish to be actively involved in their personal health care or in taking broader collective action. Desire for control can be conceptualized along three dimensions (Auerbach, 2001):

- **Cognitive/informational control** is concerned with processing relevant information and thereby reducing ambiguity and leading to an enhanced sense of control over the particular situation. In the case of health care this involves obtaining and reviewing information about the health problem and the proposed treatment.

- **Decisional control** refers to the opportunity for reviewing and selecting preferences for treatment.

- **Behavioural control** involves direct action whereby the individual is involved in changing the situation. It implies that the patient has the opportunity to select and guide the actual treatment.

There is substantial evidence that patients desire information about their health (Auerbach and Pegg, 2002). Younger, more educated patients have a greater desire for such information. In the case of decisional control, the evidence is more equivocal, with many patients indicating that they would prefer physician control or at best some form of joint or collaborative control. A variety of factors influence this preference: (1) less desire for control when the disease is serious, (2) less desire for control among older patients, and (3) less desire for control among patients with lower education. In concluding his review, Auerbach (2001: 197) concluded: ‘If there is a predisposition on the part of patients to want to assume control, it is strongly influenced by their appraisal of whether they think involvement on their part will positively influence the outcome of their situation.’

CRITICAL APPROACH TO EMPOWERMENT

Many health care providers have enthusiastically endorsed the idea of empowerment. However, there is a need for some caution as regards why this idea has become so popular and its implications for patient care. Although most physicians prefer to adopt the dominant role in patient care (Beisecker et al., 1996), there is increasing evidence that many are promoting greater control by the patient (e.g., Coulter, 1999). Indeed, this orientation connects with the identification of the patient as responsible in some way for both their illness and their treatment. This is particularly the case in those illnesses associated with lifestyle practices, such as smoking, diet and exercise, but also with chronic diseases.

This critical approach to patient empowerment considers it part of the extended biopsychosocial model (Salmon and Hall, 2003). This model extends the traditional dualistic approach to the body by identifying psychosocial factors as aetiological agents of disease. This in turn leads to concern with promoting increased control and various coping strategies as ways of patient empowerment. Implicit in this discourse is the transformation of the patient from a passive sufferer to an active manager of their own suffering ‘from which it is a small step to locating with the patient the moral responsibility to become well’ (Salmon and Hall, 2003: 1,973).
This provides the physician with the opportunity to evade responsibility for treatment of those problems for which they have limited insight (e.g., chronic illness and mental illness). Thus, the language of empowerment can serve the physician’s interests rather than those of the patient. It can also absolve the physician of responsibility for certain medical errors.

A graphic illustration of the negative impact of empowerment is the enthusiasm of many physicians to promote the so-called ‘fighting spirit’ attitude among cancer patients. Initial research by Greer et al. (1979) had suggested that patients with this attitude had better survival prospects. Many patients report that their clinicians encourage them to be positive and to fight (e.g., Byrne et al., 2002). Unfortunately, such encouragement can be disempowering as the patient feels depressed because she/he cannot control the disease. In our review of the evidence, there is no empirical support for the hypothesis that personality or coping strategies improve the prospects of survival (see Chapters 18 and 21).

Another example of this disempowering advice is the case of ‘patient-controlled analgesia’ (PCA), which is a strategy designed to provide postoperative patients with control over their analgesia. However, in interviews with the patients, it was found that PCA did not give them control over their pain. Rather, they liked PCA because it freed them of the need to exercise control by ‘bothering’ nurses with requests for analgesia (Taylor et al., 1996). In a comparison study that involved teaching postoperative patients to feel in control of their recovery, it was found that patients interpreted the programme as a request not to annoy the staff. Together, these studies question the practice of strategies designed to empower patients.

Kugelmann (1997) develops a similar critique in his review of the growth of the gate control theory of pain. He notes that an important component of this and other biopsychosocial models is the insistence on personal responsibility for pain management. The alternative to assuming responsibility is learned helplessness and passivity. While the patient is expected to assume responsibility, ‘they should not expect, however, that the professionals should relinquish their salaries or expertise’ (Kugelmann, 1997: 61). Kugelmann also connects his critique with the ignorance of social problems: ‘If pain is truly epidemic today, then something is terribly wrong, not only with patients, or “inadequate” pain technologies, but with the social matrix that produces suffering. To tempt people to be co-managers in such a social world only deepens our true helplessness’ (1997: 62).

Other researchers have questioned the whole movement towards promoting empowerment. As Lord and McKillop Farlow (1990: 2) noted: ‘People mistakenly talk about “empowering families” or “empowering professionals” as if empowerment is something one person does to another’. Powers (2003: 229) argues that rather than challenging the traditional medical paternalism, ‘empowerment equals paternalism’. Within a capitalist state, the promotion of empowerment has a hidden agenda:

- It allows health care disciplines to reframe questions regarding oppression to questions regarding free individual choices among predetermined alternatives in the context of a belief in natural rights.
- It allows the health care provider to assign blame when the strategy fails, i.e., when the patient chooses the ‘wrong’ option.
- It makes health education a technology of the self, a way to manipulate people to think they are taking charge of their own health and exercising their rights instead of being dependent.
The move towards empowerment is especially directed at those people who do not conform to mainstream values and practices rather than attempting to promote broader changes in social structures. The physician and other health professionals can now continue to disparage the most deprived and marginalized, not now for their non-compliance but rather for their refusal to accept responsibility for self-management.

These criticisms highlight the need for health psychologists to adopt a broad critical perspective so that they do not simply continue to be another agent of health care oppression under the ‘empowerment’ umbrella.

**FUTURE RESEARCH**

1. New medical procedures and drugs are constantly being developed. There is an ongoing need to assess the problems involved in their adoption in the community.

2. Large-scale prospective studies are needed to investigate the association between psychological factors and non-adherence.

3. Not everyone will accept certain procedures. Further research is needed to explore the meaning of different treatments to different populations.

4. Research needs to address how best to involve people more directly in all aspects of their health care.

**SUMMARY**

1) Adherence refers to the extent to which the patient follows the prescribed treatment regimen.

2) A wide range of social and psychological factors have been found to be associated with non-adherence. These factors are associated with the characteristics of the patients, the disorders they have, the treatments they are given, and the relationships they have with their physicians and organizational factors.

3) It is difficult to compare the results from different studies because of the complex nature of non-adherence and the variety of methods and criteria that are employed.

4) An alternative approach is to consider the impact on patient behaviour of the socio-political role of the physician and the meaning of the health problem and of the prescribed medication for the patient.

5) Medical silence has traditionally concealed the extent of medical error.

6) Medical error leads to a wide range of health problems. Explanations of medical error include both person and system factors.

7) Patient empowerment aims to involve patients in health care through listening to their needs, not as recipients but as active partners in health care.

8) Patient empowerment conversely can place responsibility for illness management on the patient and, to some degree, absolve physicians and other health care professionals from responsibilities.

9) A broad, critical perspective suggests the need for health psychologists to not simply reinforce oppressive forms of health care by positioning themselves under the umbrella of ‘empowerment’.