

## Chapter six: Supporting self-management

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### INTRODUCTION

Chronic conditions, such as diabetes mellitus, stroke and cardiovascular disease, have a significant impact on both the mental and the physical health of individuals (Mackay and Mensah 2004). The increase in the prevalence of chronic conditions represents a growing challenge to healthcare systems worldwide (Singh 2005). Some health systems have adopted a system-wide approach based on a framework such as the Chronic Care Model (Wagner et al. 2001) (Chapter 4) while others focus on specific elements of care or target people who are intensive users of services or at greatest risk of hospitalization (Singh 2005). Given the long-term nature of these conditions, governments and health service providers are engaged in initiatives to develop new ways of supporting people living with chronic conditions to manage their own health. There is increasing recognition that reduced risk and improved outcomes cannot depend solely on the actions of health professionals but are also contingent on the individual's own actions.

Support for people to self-care is, therefore, a vital element of any policy to tackle the rising tide of chronic disease.

This chapter will clarify the definitions of terms such as self-care, self-management and self-management support and will detail the theoretical approaches that underpin many self-management support interventions. The nature and effectiveness of self-management support in chronic disease will be analysed critically, highlighting the challenges of providing such support to people with multiple conditions, or who experience social deprivation. This analysis will be illustrated with examples from selected countries. Finally, we will identify health system facilitators that are necessary for the implementation of self-management support. As such, this chapter will be of interest to policy makers and providers engaged in the redesign of services to improve the quality of chronic disease management.

### DEFINING SELF-CARE, SELF-MANAGEMENT AND SELF-MANAGEMENT SUPPORT

The concept of self-care features prominently in policy documents in many countries, for example the United Kingdom *NHS Plan* (Department of Health 2005) and the Danish strategy for the management of chronic conditions (National Board of Health 2005a, 2005b). Similar policy initiatives in Australia refer to self-management (Walker et al. 2003). The concept of self-management support is also used in most countries (Glasgow et al. 2003). There is a lack of clarity and some overlap in the way these terms have been defined and used in current policy and research since the early 1990s (Bentzen et al. 1989; Dean 1989; Haugh et al. 1991; Meeto and Temple 2003) (Table 6.1).

#### Self-care

The WHO defines self-care as, “the activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health” (WHO 1983). The Department of Health (2005) uses a similar but slightly elaborated definition of self-care: “the actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and well-being after an acute illness or discharge from hospital.” These definitions reflect the fact that self-care skills and knowledge stem from lay

experience and suggest that self-care is a part of daily living. Some definitions emphasize that self-care involves a partnership between health service users, their carers and health professionals (NHS Scotland 2005), others suggest self-care activities may exclude healthcare professionals (Eales and Stewart 2001). Self-care can include a broad range of activities ranging from doing nothing in a particular situation (Haugh et al. 1991), or taking pain killers for a headache, to a patient developing expertise in managing a long-term condition (NHS Scotland 2005). Self-care may include behaviour and actions taken by those who are healthy, at risk of ill health, experiencing symptoms, diagnosed with an illness or receiving treatment. Thus, it encompasses specific types of self-care such as self-diagnosis, self-management, self-medication and self-monitoring.

#### [TABLE 6.1]

##### **Self-management**

The term self-management was first used by Creer in the mid 1960s to denote the active participation of patients in their treatment (Koch et al. 2004). The aim of self-management is to minimize the impact of chronic disease on physical health status and functioning, and to enable people to cope with the psychological effects of the illness (Lorig and Holman 1993). Self-management is described as a collaborative activity between patient and healthcare practitioner (Lorig 1993). Self-management activities are usually undertaken by the patient between planned contacts with healthcare practitioners and services. These activities involve managing symptoms, treating the condition, coping with the physical and psychosocial consequences inherent in living with a chronic condition and making lifestyle changes (Glasgow et al. 2003). At-home management tasks and strategies are undertaken with the collaboration and guidance of the individual's physician and other healthcare providers (Clark et al. 1991). As such, self-management is not regarded as an option but rather as an inevitable series of activities that should be an integral part of primary care (Glasgow et al. 2003).

##### **Self-management support**

Self-management support involves a patient-centred collaborative approach to care to promote patient activation, education and empowerment (Goldstein 2004). Self-management support expands the role of healthcare professionals from delivering information and traditional patient education to include helping patients build confidence and make choices that lead to improved self-management and better outcomes (Coleman and Newton 2005). Selfmanagement support is a key feature of the Chronic Care Model, which emphasizes the centrality of an informed, activated patient to productive patient-provider interactions (Glasgow et al. 2002).

Self-management support includes patient education, the collaborative use of a wide range of behavioural-change techniques to foster lifestyle change, the adoption of health-promoting behaviours and skill development across a range of chronic conditions (Farrell et al. 2004). Patients are trained in problem solving, goal setting, and the use of evidence-based standardized interventions in chronic conditions such as diabetes (Coster et al. 2000; Balas et al. 2004), heart failure (Ara 2004), hypertension (Khan et al. 2005) and angina (McGillion et al.

2004). Collaborative care planning is an important way in which individual providers can support self-management. A collaborative care plan not only focuses on the medical management of the condition but also facilitates role management, negotiation of behaviour change necessitated by the chronic disease, and management of the emotional impact of living with a chronic disease (Fuller et al. 2004).

Self-management support may be delivered through standardized, programmatic interventions. Programmes generally target the way the person with the chronic condition thinks or represents his or her illness. They include a range of cognitive-behavioural

interventions, with the goals of such programmes directed at self-efficacy beliefs, health behaviour, health status and reducing the number of unplanned hospitalizations (Dongbo et al. 2003). The aim of selfmanagement support programmes is to prepare patients to engage with medical management, to maintain life roles and to manage negative emotions such as fear and depression by offering patients the opportunity to acquire the necessary knowledge, skills and confidence (self-efficacy) to deal with disease-related problems. In this way they seek to improve the quality of chronic disease management (Goldberg et al. 2003, 2004).

### **THE THEORETICAL BASIS OF SELF-MANAGEMENT SUPPORT**

Most self-management support provided to people with chronic conditions aims to influence their behaviour in some way. People living with one or more chronic diseases are expected to undertake a variety of activities to manage their condition and may need to modify their behaviour in order to minimize the impact of the illness and to prevent further deterioration. For example, they may need new skills or knowledge to use aids and devices, to manage symptoms and pain, to take medications as directed or to cope with the limitations of their illness. They may be advised to take more regular exercise, control their weight, modify their diet, give up smoking or reduce their alcohol intake. Many selfmanagement support interventions are based on one or more theories of human behaviour. For example, techniques such as motivational interviewing and brief negotiation explicitly claim to draw on theories such as self-perception theory (people are more powerfully influenced by what they hear themselves say than by what others say) and decisional balance theory (decision making can be facilitated by weighing the advantages and disadvantages of a certain issue) (Kaiser Permanente 2005).

Table 6.2 summarizes some of the key behavioural theories and gives examples of relevant self-management support interventions. These theories are not mutually exclusive and many theories adopted and adapted earlier ideas. They provide different ways of thinking about what motivates behaviour change.

An appreciation of the basic ideas behind theories of human behaviour is useful to understand both the appropriateness and the likely effectiveness of self-management support.

#### **Rational choice theory**

Theories of decision making that derive from utility theories date back to the work of Jeremy Bentham (1748–1832) and John Stuart Mill (1806–1876), and are used widely in economics and political science, and assume that individuals seek to maximize their welfare when taking action or making decisions. Rational decision making assumes that, when faced with a number of alternatives, people choose an action in line with stable preferences by weighing the expected costs and benefits. In the case of health behaviours, rational choice suggests individuals will only change their behaviour or adopt new behaviours where they perceive that the value of doing so outweighs the costs. If people are not fully informed about the outcomes of a particular behaviour or action, this might present a significant barrier to effective selfmanagement.

#### **[ TABLE 6.2 ]**

Therefore, educational interventions that seek to increase knowledge about a person's condition, available treatment options and preventive and management strategies are an important element of self-management support. Nevertheless, knowledge about the impact of behaviours does not necessarily lead to behaviour change. Strategies such as increasing the costs of risky behaviours, for example by taxing cigarettes, or subsidizing the costs of beneficial behaviours, as with vouchers for gym membership, are also used to modify behaviour. Economic incentives are effective in simple preventive care and for distinct, well-defined behavioural goals. There is less evidence that financial incentives can sustain long-term lifestyle changes (Kane et al.2004). The rational approach to decision making has been

criticized from a number of perspectives: there are limits on our ability to appraise all options rationally (Simon 1957), people use mental shortcuts to make decisions (Tversky and Kahneman 1974) and preferences are often unstable and can be shaped by the way in which information is presented (Lichtenstein and Slovic 2006).

### **Theory of planned behaviour**

According to the theory of planned behaviour, behavioural intentions are determined largely by attitude (beliefs and evaluation of the outcomes), subjective norms (i.e. perceived social pressure) and perceived behavioural control (self-efficacy) (Fishbein and Ajzen 1975; Ajzen and Fishbein 1980). A similar model, referred to as the attitude/social influence/self-efficacy model, is an extension of the original theory but includes self-efficacy as a third component (De Vries et al. 1988). Interventions built on this model focus not only on influencing people's attitudes to the behaviour and their perception of the outcomes (i.e. is it worth it?) but also on external influences on behaviour (i.e. is this the right or acceptable thing to do?) and whether people are confident to take action (i.e. can I do it?).

### **Self-regulation model**

An individual's beliefs about symptoms, the causes and prognosis of the illness and the possibilities for control are known as illness representations. Research since the 1970s has demonstrated the importance of illness representations to patient behaviour (Petrie and Weinman 1997). They have been linked to health-related outcomes such as depression and quality of life (Leventhal et al. 1980, 1984). Situational stimuli (such as symptoms) generate both cognitive and emotional representations of the illness; people adopt behaviours to cope with them and then appraise the efficacy of these behaviours. Changing patients' illness representations has been shown to improve recovery following myocardial infarction (Petrie et al. 2002) and patient outcomes for conditions as diverse as diabetes and the acquired immunodeficiency syndrome (AIDS) (Petrie and Broadbent 2003).

### **Trans-theoretical model of change**

The trans-theoretical or transactional model focuses on the motivation or intention to change (Prochaska and DiClemente 1983). It identifies a series of motivational steps that have to be taken in order to change behaviour: precontemplation, contemplation, action, maintenance and relapse. The "stages of change" theory of human behaviour has been applied widely in health education and promotion, for example smoking cessation, condom use, weight loss, alcohol abuse, drug abuse and stress management.

The stages of change have also been applied to self-management and in this context "refer to a fixed sequence of psychological and behavioural states that patients move through from lacking the motivation to adopt new self-management behaviours in the beginning to having integrated the new behaviour in their life at the end" (Dijkstra 2005). Researchers have tried to classify people with chronic conditions according to the stages of change. The idea is that patients in different stages benefit from different types of selfmanagement support. Such an approach to classifying theoretically derived stages may, however, oversimplify the reality.

### **Social cognitive or social learning theory**

Bandura's (1977, 1997) social learning theory postulates that behaviour is influenced by outcome expectations (beliefs about the effectiveness of the behaviour, for example the advantages and disadvantages of an action), observational learning (social influences including social norms, social support or pressure, and the behaviours of others, also called modelling) and self-efficacy expectations (beliefs about the individual's ability to perform a particular behaviour or to change a specific cognitive state successfully regardless of circumstances or contexts). Improving the self-efficacy beliefs of patients is a key element of many self-management support interventions (Lorig et al. 2001).

Use of peer modelling (i.e. using other patients as role models) and peer support are approaches grounded in this theory.

There is considerable evidence that self-efficacy plays an important role in the likelihood of adopting and maintaining health behaviour changes and is associated with improved affect, heightened motivation, better function, treatment adherence and improved clinical and social outcomes (Marks et al. 2005a, 2005b).

### **Stress-coping model**

A chronic illness is seen as a major life event, characterized by a number of recurrent stressful situations that pose serious challenges to adaptation (Moos and Schaeffer 1984; Zautra 1996). People with chronic conditions face a range of stressors. For example, those with diabetes might have to adhere to a complex dietary regimen and perform self-management tasks on a daily basis. Patients with arthritis have to deal with pain, disfigurement, loss of functional ability and periods of remission. Their ability to cope with these stressors influences how well they can maintain adequate levels of physical, social and emotional functioning. Interventions based on the stress-coping model emphasize coping strategies and teach patients adaptive coping strategies. Many interventions try to improve coping by enhancing social support and personal coping resources, such as feelings of mastery, self-esteem or self-efficacy. Interventions ranging from cognitive – behavioural therapy and psychotherapy to education and support groups are linked with this theory.

### **Self-determination theory**

Self-determination theory (Deci and Ryan 1985) emphasizes the importance of autonomy. According to this theory, healthcare practitioners must maximize the natural motivation of patients. “Motivation refers to the psychological forces or energies that impel a person towards a specific goal” (Sheldon et al.

*2003*). *A patient’s motivation to participate in self-management is predicted by the extent to which healthcare practitioners support autonomy and the extent to which an individual feels him or herself-responsible for initiating and maintaining that behaviour.*

### **Summary of behavioural theories**

In summary, understanding the theories that underpin human behaviour is important in order to design and assess interventions that support individuals in managing their condition. Self-management usually requires people to adopt new behaviours. The theories reviewed here suggest that interventions to support people in taking action to improve their health and manage their condition require a range of strategies depending on each person’s level of knowledge, his or her illness and health beliefs, his or her attitudes towards the behaviour, the level of confidence, strength of social networks and the level of motivation.

The support that is needed will vary for people in different social circumstances (as we shall see below), at different stages in their disease and with different skill levels (e.g. literacy). A wide range of interventions have been developed based on these theories, including those that involve the provision of educational support, financial incentives, peer support groups, motivational interviewing, problem solving, goal setting, action planning and strengthening coping skills.

The next section will describe these interventions and summarize the evidence for their effectiveness.

### **Self-management support programmes: scope and effectiveness**

Self-care interventions have been systematically reviewed elsewhere (Coulter and Ellins 2006). Here we provide an overview of self-management support programmes, by which we mean standardized interventions developed for specific target groups (e.g. elderly people, patients with diabetes, parents of children with asthma). As we have seen, self-management requires people with chronic conditions to undertake a variety of demanding tasks. It is, therefore, not surprising that many people with chronic conditions find it difficult to self-manage successfully, and patients may benefit from participating in selfmanagement support programmes that aim to develop the attitudes and skills necessary for successful self-

management. Since the early 1990s, there has been a substantial increase in the number of self-management support programmes used internationally, although the approaches vary. Box 6.1 provides selected examples of self-management support programmes.

### **Target population**

The majority of self-management support programmes focus on people with a single disease. Barlow et al. (2002) showed that most interventions are designed to address either asthma or diabetes, or more rarely arthritis and heart disease.

A respiratory rehabilitation programme for people with chronic obstructive pulmonary disease developed in Canada aimed to support patients to maintain optimal physical, psychosocial and mental functioning levels (Bourbeau et al.

2003). The programme was shown to reduce the number of admissions to hospitals and visits to the emergency department. It also showed an enhanced use of primary health services and improvement in the patients' quality of life.

### **[BOX 6.1]**

Some support programmes are not disease specific but generic in design.

These generic programmes address the needs of people with multiple comorbidities or those with chronic disability, often older patients. The Chronic Disease Self Management Program (CDSMP) (Lorig et al. 2001) is probably the best example of such a generic programme (Box 6.1).

Most support programmes target the person with the chronic condition.

Carers and family members may accompany the person to one of the sessions but self-management support programmes exclusively designed for carers or family members are rare. Where they do exist, they mainly focus on carers of chronically ill patients who are dependent on intensive home care, for instance those with stroke, dementia or in a terminal phase of their illness. In these programmes, most attention is paid to helping the carer to deal with the emotional aspects of living with and caring for a person in need of intensive care. Few are designed specifically to help partners and other family members to provide positive self-management support to the patient (Clark and Dunbar 2003). The Family Partnership Intervention is an example of a support programme that focuses on developing supportive skills among family members of patients with heart failure (Clark and Dunbar 2003). A major part of this support programme aims to teach family members to use behaviours supportive of autonomy, such as expressing empathy and concern, providing a rationale for self-management, emphasizing the choice a patient has, reducing critical or guilt-provoking language, and helping the patient with problem-solving behaviours. However, further research is needed on the value of support programmes for partners or family members.

The majority of self-management support programmes target adults; few focus on children. There are exceptions, especially in the field of asthma, where several programmes are designed for both children and adults. Many programmes that are offered to children were originally developed for adults and insufficiently account for the developmental stage of the child (Mokkink et al. 2007). Most support programmes are only used in the country where they have been developed and few have been adapted for use in different countries or cultures.

An exception is the Arthritis Self Management Program (ASMP), which was developed at Stanford University but has been delivered in a number of countries outside the United States including Denmark, the United Kingdom, the Netherlands, Australia and Canada (Barlow et al. 2002). The CDSMP has also been adapted for use in the UK (known as the Expert Patient Programme) and Canada (British Columbia and Alberta; known as Live Better Everyday), and the National Board of Health in Denmark has recommended that it should be implemented nationwide following a successful trial (see accompanying volume).

## **Content**

Lorig and Holman (2003) reported that most interventions address medical or behavioural management tasks, whereas a minority also pay attention to role management and/or emotional management. This, however, depends on the disease process involved: support programmes for patients with cancer are more likely to address the emotional aspects of the disease than programmes for patients with asthma, where correct use of medication comes first. Interventions that focus primarily on medication and symptom management are necessarily disease specific. Interventions that include management of psychological consequences (e.g. depressed mood), lifestyle (e.g. exercise), social support and communication are usually generic but can also be designed for individual diseases.

Early self-management programmes often lacked a sound theoretical basis or the theoretical principles were not explicit. As noted above, many of the current programmes are based on social learning theory developed by Bandura (1977, 1997) and focus on building self-efficacy or use self-regulation principles. It has been noted that support programmes for patients with diabetes and arthritis are generally more theory based than programmes for patients with asthma, for which interventions are mainly information based and instructional, with only a few incorporating techniques to address barriers to self-management (Newman et al. 2004).

## **Other characteristics of self-management programmes**

Self-management programmes can be group based, developed for the individual or a combination of both. Groups typically have between 6 and 12 participants and often use written materials. Programmes for an individual can range from provision of a manual that participants work through at home to sessions with a health professional on a one-to-one basis in a clinical setting.

Most interventions are administered by health professionals such as medical doctors, psychologists and nurses. For example, in Australia, diabetes selfmanagement education is provided largely by specialist nurses and dieticians through diabetes centres. In Sweden, the majority of self-management support for diabetics is given in nurse-led clinics. The CDSMP in the United States and the Expert Patient Programme in the United Kingdom use lay tutors with chronic conditions who are trained to deliver the intervention. An evaluation of Expert Patient Programme found that the perceived success of the group depended on the facilitation skills of the lay leader (National Primary Care Research and Development Centre 2007).

Most self-management programmes are offered within a clinical setting, such as a hospital or a rehabilitation centre. In some countries, the voluntary sector or patient organizations have traditionally run self-management programmes.

For example, in France, diabetes networks have developed patients' guides and newsletters with instructions on foot care, insulin injections, fat intake reduction and exercise (REVESDIAB). In Canada, the provincial health systems are beginning to take a more active role in investing in self-management support programmes, having previously relied on diabetes and cancer associations.

Increasingly self-management support programmes are funded as part of the public health system.

## **Effectiveness**

For policy makers and providers, the main question is whether people with chronic conditions benefit from self-management support programmes. The answer is not straightforward. Systematic reviews and meta-analyses suggest that most programmes show positive results, but rarely on all outcome indicators that were measured.

Chodosh et al. (2005) carried out a meta-analysis of 53 randomized controlled trials on self-management interventions focusing on elderly patients with diabetes, hypertension or osteoarthritis and concluded that mostly beneficial effects were found on clinical outcomes such as blood glucose level (diabetic patients) and blood pressure (patients with

hypertension), but not on outcomes such as pain and functional status (patients with osteoarthritis) and weight (diabetic patients). An explanation suggested by the authors is that programmes that address medication adherence may be particularly effective.

Two Cochrane reviews have examined the effectiveness of self-management support programmes. The first concerned self-management programmes for adults with asthma (Gibson et al. 2002). The interventions studied provided self-monitoring of symptoms and regular review by clinicians as well as use of written action plans. The authors found evidence that participation in these programmes had beneficial effects on the course of the disease: patients who had joined a self-management support programme had fewer hospital admissions and emergency department or unscheduled medical office visits; they reported fewer night time symptoms and less sickness absence from work or school. The second Cochrane review (Riemsma et al. 2002) focused on the effects of self-management support programmes for patients with rheumatoid arthritis. The interventions consisted of patient education combined with several other approaches, such as psychobehavioural methods, exercise, biofeedback and psychosocial support. There was evidence that the programmes had beneficial effects on functional status, the number of affected joints, self-reported health and overall psychological status, but not on the level of pain, anxiety and depression. The positive effects were found shortly after attending the support programmes; long-term benefits could not be established.

Lorig and Holman (2003) described the results of randomized trials conducted by the Stanford Patient Education Research Center of their own selfmanagement programmes (e.g. CDSMP, ASMP). In general, they found positive effects on the frequency of behaviours such as exercising and symptom management.

In all studies on patients with arthritis and back pain, patients experienced a reduction of pain; in most of these studies they also found disability to be reduced. Furthermore, participants reported improved communication with their physicians. In two studies, one with the English version of the ASMP and one with the generic CDSMP, significant reductions in healthcare utilization were also found. A randomized trial to assess effectiveness of the Expert Patient Programme in the United Kingdom found improvements in self-efficacy and energy levels among patients with chronic conditions, with some evidence of a (small) reduction in associated costs (Kennedy et al. 2007).

Barlow et al. (2002) conclude from several randomized clinical trials that self-management support programmes are effective in increasing knowledge, symptom management, use of self-management behaviours and self-efficacy, and promote beneficial medical outcomes.

Based on a systematic review, Coulter and Ellins (2006) concluded that educational programmes that teach practical self-management skills appear to be more effective than information-only patient education. Findings from studies evaluating self-management education were mixed, however, as there was a general association with improvements in knowledge, coping behaviour, adherence, self-efficacy and symptom management. The review found limited evidence for reductions in health service utilization, cost and enhanced quality of life but identified the following factors as being associated with larger effect sizes: longer and higher intensity interventions, regular review with health professionals, focus on specific rather than general educational topics, participative rather than didactic teaching methods, multicomponent approaches and involvement of informal carer or family members.



### **Methodological considerations**

These studies have a number of limitations that need to be acknowledged. First, the follow-up period of the evaluation studies described above is seldom longer than 12 months and mostly shorter than six months, which makes it difficult to draw conclusions about the long-term effects of self-management support programmes. Second, although most support programmes show beneficial results, at least in the short term, none of the above-mentioned studies linked specific components of the programmes to outcomes. Most programmes are multicomponent, but the studies often fail to describe interventions in sufficient detail to allow a thorough understanding of them. This means that we still do not know which approaches, techniques or elements of self-management programmes are most successful and should, therefore, be developed in future.

Lorig and Holman (2003) observed that enhanced self-efficacy is one key mechanism responsible for improvements in health status among those attending self-management programmes. They concluded that self-efficacy should form a key component in future self-management support programmes. Further research on this question is needed in order to prevent programmes being offered that include unnecessary components and so waste time and money.

The comparative effectiveness of generic and disease-specific programmes also needs further evaluation. Clark and Dunbar (2003) contended that support programmes that teach basic problem-solving and self-regulatory skills may be successful for many people irrespective of their specific chronic condition.

Such programmes may be promising for people with rare diseases and the many people who have multiple chronic conditions for whom disease-specific support programmes are either not available or are inadequate. Coulter and Ellins (2006) found different results of self-management education with different diseases.

Education for people with asthma was found to reduce health service utilization, with improvements in quality of life and self-efficacy, while education for people with arthritis had only a small and short-term impact on pain and functional disability (Coulter and Ellins 2006).

Only a few studies have analysed the cost-effectiveness of programmes (e.g.

Kennedy et al. 2007). Those that have, mostly focused exclusively on the direct costs of the self-management programme, rarely considering the indirect costs to the participant (e.g. time off work or for substitute care, travel expenses etc.).

It seems plausible that some interventions will be cheaper than others: peer-led programmes will probably be less expensive than programmes provided by medical personnel, group-based approaches less expensive than providing individual support, and offering the programme in community buildings less expensive than programmes provided in a clinical setting. These potential differences in costs have not, however, been systematically assessed.

### **RESPONDING TO THE SUPPORT NEEDS OF DIFFERENT PATIENTS**

Despite the variety of self-management support programmes available, they may not be appropriate for everyone with a chronic condition. Here we identify at least three groups where greater (or different) self-management support may be needed: those with complex needs, those with limited resources and those who are not motivated.

#### **Complex needs**

Some groups of patients have particularly complex self-management tasks, such as those with multiple chronic conditions, the frail elderly and patients with severe or various impairments and disabilities (Bayliss et al. 2003; Young 2003; Levine et al. 2006; Suhl and Bonsignore 2006). Such people are usually excluded from participation in standardized interventions that are evaluated by randomized clinical trials. Moreover, the existing support programmes – especially those that are disease specific – may not be relevant to the specific

selfmanagement support needs of patients with multiple comorbidities or chronic disability. Bayliss et al. (2003) reported that patients with multimorbidity often experience “competing demands” arising from their chronic conditions. Furthermore, engaging in activities to promote physical or psychological health may be hindered by comorbid conditions. For example, a person who is obese and has diabetes and who is advised to exercise may feel constrained from doing so because of coexisting arthritis. Also, depression or other mental disorders, which are concomitant conditions in many chronically ill people (Verhaak et al. 2005), have been found to impact adversely on self-management performance (e.g. Ciechanowski et al. 2000). Data from the Dutch National Panel of the Chronically Ill and Disabled shows that, in 2005, levels of self-reported inactivity were significantly higher among patients with severe disability compared with people with no/mild disabilities (Table 6.3) (Rijken et al. 2005).

Tailoring of self-management support is in its infancy and so there is no evidence to guide policy makers as to the best approach. However, some interventions appear promising in this respect. Generic self-management support programmes that focus on the development of self-efficacy and problem solving and how to integrate self-management behaviours in daily life may be effective for patients with multiple morbidities or chronic disability. A disability approach (Heijmans et al. 2004), in which the generic disabilities of people with different chronic diseases in the social, emotional or physical area are taken as a starting point for intervention, may also appeal to patients with complex needs. Computer-based decision support tools have been developed that enable telephone-based nursing staff to counsel patients with multiple comorbidities to help them to focus on those self-management activities that evidence suggests will be most effective in bringing their condition under control. For example, a patient with diabetes and ischaemic heart disease will have to combine activities aimed at lipid lowering and glucose control (Mulley 2006). Other work is needed to establish meta-guidelines and information resources that recognize the interdependencies experienced by people with multiple comorbidities.

### **[TABLE 6.3]**

Most existing information and decision support tools are disease specific.

Finally, supporting people to manage mental as well as physical conditions will be important. Some providers are considering routine screening for depression and its treatment before embarking on self-management programmes for chronic physical conditions.

Levine et al. (2006) have warned that frailty “is not just the sum of several disease conditions”: many frail elderly people do not only suffer from multiple diseases; cognitive impairments and poor mental health often also coexist.

They argued that more research is needed to find out which disease management approach best meets the needs of the frail elderly. They predicted that approaches which respond to both the social and medical needs of frail elderly people and their caregivers will be most effective.

### **Lack of resources**

Some people with chronic conditions may have inadequate access to resources to perform successful self-management or to attend support programmes.

Although self-management support programmes are designed to develop resources such as knowledge, communication skills, effective coping strategies, social support and self-efficacy, a basic level of these resources is needed to be able to benefit from self-management support: patients need to be informed about the existence of such programmes; they need to speak the same language as the programme leader and other group members; they need to be sufficiently literate to be able to read and understand the accompanying written materials; and they must be able to reach the location and to afford the costs of participation or know how to get reimbursed where relevant. Reaching diverse and disadvantaged groups has been a challenge for CDSMP courses (National Primary Care

Research and Development Centre 2007). Patients tend to be especially disadvantaged if they are older, are less educated, are on low incomes or do not have health insurance, have cognitive or intellectual impairments, or belong to an ethnic minority (Glasgow et al. 1997; Becker et al. 2004; Rothman et al. 2004; Suhl and Bonsignore 2006).

A 2005 study from the Netherlands of patients with chronic conditions found that those on lower incomes were significantly more likely to be inactive than those in high-income groups (Table 6.3). Understanding of medication was lower among those with less educational attainment (Table 6.4; Heijmans 2006). Similar examples can be found elsewhere. For instance, Becker et al. (2004), in a qualitative study among African-Americans suffering from chronic illness, found that regular exercise was reported less often by respondents who were uninsured. Those who had some form of health insurance had many more opportunities to discuss their illness and self-management problems with physicians and other health professionals.

#### [TABLE 6 4]

Disadvantaged groups will benefit from basic patient education (“what to do and why”) before addressing their skills and confidence to carry out these self-management tasks (“how to do things”). Individual support from a clinician involved in their care could be appropriate, or a group consultation with other patients with the same condition, preferably complemented with written or audiovisual education material in the patient’s native language. In some countries, patients are simply not getting access to basic education about their condition. For example only 28% of people with diabetes in Ontario had access to structured education (see accompanying volume).

Once basic patient education and counselling has been provided, ongoing support, involving goal setting and action planning, with regular review and problem solving can help these patients to gain the skills and confidence they need to take on self-management tasks. This could either be provided by a health professional from their care team or health coaches accessed by telephone.

Referral to financially and physically accessible community self-management programmes can be considered once the patient feels confident and motivated to attend a support programme (Coleman and Newton 2005).

#### **Lack of motivation**

The third group of chronically ill patients who appear not to be served well by existing support programmes are those who lack motivation. Barlow et al.

(2002) referred to this group as patients who “may not feel able to embrace the concept of self-management”. Since attendance at self-management support programmes is voluntary, participants must be willing to improve their selfmanagement, or at least to think about it seriously (Dijkstra 2005). Patients who are not motivated to adopt healthy behaviours are unlikely to benefit from support programmes that focus on enhancing self-efficacy and formulating personal action plans. These patients generally know “what to do”, but not “why”.

In terms of the trans-theoretical model, these patients find themselves in the precontemplation phase. Barlow et al. (2002) noted that patients “may need support in making the transition from precontemplation to contemplation of making self-management a part of their lives”. The patient activation model, developed and validated in the United States, sees such patients as having the lowest level of knowledge, skills and confidence and consequently failing to recognize that they have an active role to play in their health (Hibbard et al. 2005). By identifying which behaviours are realistic for patients at different stages of activation, it is possible to encourage them to take appropriate “next steps” suited to their level of knowledge and skill (Hibbard and Tusler 2007).

Unfortunately, very little is known about how to support patients in making this step. Further research is needed to understand why these patients lack motivation to self-manage

and to explore their illness representations, as described earlier in this chapter. When patients consider their condition to be not very serious or do not experience any symptoms, they will feel less motivated to self-manage. Patients may also not believe that they can influence their health or control their disease, either by following medical advice or by selfcare.

False beliefs about the causes of their illness, its course and consequences, as well as the benefits of adequate self-management may be corrected by interventions that aim to develop autonomous behaviours. This may be by providing information relevant to the patient's personal goals, use of role models appealing to the patient, monitoring and feedback on progress, or creating peer support through "buddying". In addition, healthcare providers may wish to involve partners or other important members of the social network in the selfmanagement process. This can be helpful for all patients but may be essential for patients who lack intrinsic motivation.

While there are many benefits from systematizing the care of people with chronic conditions (Chapter 4), self-management support must be tailored to the needs of the individual. Self-management support interventions need to be developed and evaluated with this in mind. However, further research is needed to understand the barriers to self-management that different patients experience.

In summary, proactive teams will make use of standardized assessments of patients' levels of self-management in different areas, including skills to manage their illness and confidence in minimizing barriers to self-management and gaining access to support. We have suggested that the support people will need might depend on the nature and number of their chronic conditions or their level of disability; their education, age, ethnicity, language, culture and income; their skills, knowledge and confidence to self-manage; and their beliefs, attitudes, readiness to change and motivation. Tools are needed that can be used easily in clinical practice to explore the kinds of self-management problem faced by patients so that appropriate self-management support can be provided.

#### **BUILDING A HEALTH SYSTEM THAT SUPPORTS SELF-MANAGEMENT**

It is only in recent years that healthcare providers and health insurers have recognized how crucial self-management support is to the achievement of better outcomes. If self-management is critical to good outcomes for patients and there is evidence that interventions can improve patients' ability to self-manage, what does it take to build a system that supports self-management? Self-management requires a whole system approach. Glasgow et al. (2003) defined self-management support as a "process of making and refining multilevel changes in healthcare systems and the community to facilitate selfmanagement".

The healthcare system must give providers incentives to promote self-management (Chapter 9). In a system where providers are rewarded for more activity, they will be keen to see patients frequently, even if this brings little benefit to the patient, and even if it disadvantages them given the cost of travel and lost work. Patients can be trained to undertake much routine monitoring, such as blood pressure, blood glucose levels and peak respiratory flow. Capitation payments covering at least a year of care or outcome-related payments offer incentives to promote self-management. Financial incentives, in particular clinician rewards, are being used in a number of countries to drive changes in how patients with chronic diseases are supported (e.g. contracts for general practitioners in the United Kingdom and the Netherlands, and Pay for Performance within Medicare in the United States). Providers must also be given resources to support self-management. For example, in Ontario there is a commitment in the Physician's Service Agreement 2004 that the Ontario Health Ministry will identify and distribute appropriate self-care material to patients enrolled with a Family Health Team (see accompanying volume).

Physicians require training in how to support patients most effectively.

Tattersall (2002) contended that many healthcare professionals feel uncomfortable with the idea of empowering their patients. Active participation of chronically ill patients in the

management of their disease depends not only on the willingness and ability of the patients but also on positive attitudes and appropriate skills in their healthcare professionals. Support for self-management requires a fundamental shift in the patient–provider relationship. Encounters may require more time, they may be more educational in content and they will demand new skills from health professionals (Chapter 7). In Australia, following a series of 12 demonstration projects, the government is investing AU\$515 million (316 million) over five years in self-management. The majority of resources are going into education about self-management for health professionals, in particular general practitioners (see accompanying volume). In France, in contrast, the legal framework makes substitution and delegation of tasks by doctors difficult and does not encourage educational approaches to self-management support.

Doctors who wish to maintain their professional authority and expect patients to comply with medical advice may undermine other efforts to support patients to self-manage. Endorsement for self-management activities and active referral to self-management programmes by doctors are rare in many countries.

The national evaluation of the Expert Patients Programme in the United Kingdom found that professionals had not engaged in the process and few referred people to courses or knew about their content or rationale (National Primary Care Research and Development Centre 2005).

Self-management support should not be confined to efforts of individual healthcare providers. Support for self-management requires extensive coordination.

This includes scheduling group visits for patients with comparable chronic conditions, using disease management guidelines as prompts to structure consultations, providing systematic support by regular phone calls (especially by nurses), and generating feedback or reminders by email or text messaging (short message system; Coleman and Newton 2005). Other changes might include giving patients access to non-physician members of the care team, providing alternative contact methods (e.g. telephone, email or drop-in visits (either individual or group)), giving patients access to electronic medical records, preparing patients for the consultation using agenda-setting tools, engaging patients in their care using goal setting and action planning tools, offering opportunities for peer-to-peer mentorship, and designating a care coordinator or advocate (Bergeson and Dean 2006). Where possible, self-management support also should be accessible via the Internet and call centres. An example of this approach is the Internet-based Australian government initiative “HealthInsite”, which provides quality information on a range of health topics. Call centres extend this concept. Health First in the Australian Capital Territory provides a comprehensive health website on health and related services, easy access to health information and telephone contact with registered nurses giving health advice 24 hours a day, seven days a week (ACT Government 2007).

Group and community interventions such as weight-loss programmes and walking buddies require little direct support from the health system. However, schemes such as “exercise on prescription”, which provide professional endorsement or financial subsidies, may increase take up, particularly among patients who are less engaged or from poorer backgrounds. Providers and insurers may need to promote awareness of community resources and their benefits to both the public and clinicians. More-advanced self-management tasks, for example when a patient monitors and reports clinical indicators associated with his or her condition, may require access to telecare and home monitoring devices.

Results can be recorded automatically in the patient’s electronic medical record and be available to view via a secure Internet connection, so enabling patients to track their progress over time. This requires investment in information technology and assistive technologies (Chapter 8).

The Chronic Care Model recognizes that self-management and the active relationship between a patient and the provider are embedded within the health system and the wider

social environment. Policy makers should ensure that systems, organizations, individual professionals and the community all facilitate the patient to self-manage successfully.

### CONCLUSIONS

In this chapter, we have focused on self-management as we view this as the most important element of self-care that applies to people with chronic conditions.

Self-management requires individuals to take action to change their behaviour.

Most individuals will need support in order to be successful in this role. In designing and evaluating self-management support, it is important to draw on our understanding of human behaviour. This brief review shows that there is some evidence that self-management support programmes improve outcomes, but more research is needed to understand which components impact on which outcomes and whether improvements are sustained over the long term. Support programmes vary in their design and content. More tailoring of self-management support is needed to ensure that it meets the needs of different people.

Although self-management support is recognized as an important element of chronic care, few countries seem to be developing or implementing systematic strategies to support this process. Data from a cross-national survey of “sicker adults” in five countries in 2004 found that significantly fewer respondents in the United Kingdom and United States reported that their doctor had given them clear advice on what to do and what symptoms to watch for compared with those in Australia, Canada and New Zealand (Coulter 2006; Davis et al.

2006). Fewer than two out of three respondents in all of these countries reported that the doctor gave them a plan for managing care at home, with as few as 37% reporting this in Germany (Coulter 2006). It is vital that health policy makers, insurers and providers create systems that enable all patients to self-manage effectively.

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**TABLES AND BOX**

**Table 6.1** Self-care, self-management and self-management support for chronic conditions:key characteristics

	<i>Who is involved</i>	<i>Goals or targets</i>	<i>What is involved</i>
Self-care	Broad spectrum: ranges from the individual to the person/patient, families and communities in collaboration with healthcare professionals and healthcare systems; healthcare professionals need not be involved	Optional Prevention of disease and accidents, limitation of illness and restoration of health Improvement in the existing state of health, which may be associated with a chronic condition Changes in lifestyle, maintenance of optimal levels of health Recovery from minor ailments and following discharge from hospital	May include doing nothing Taking responsibility for health for self, children, family and helping others Asserting control Managing emotion Goal attainment and behavioural change (Hobbs et al. 1999)
Self-management	More focused networks Patients, peers, healthcare practitioners and support networks Includes healthcare professional as collaborator with the person with the chronic condition	Desirable prerequisite Minimization of the impact of chronic disease on physical health status and functioning; coping with the psychological effect of the illness Minimization of pain; patient participating in decision making about treatment, gaining a sense of control over their lives Initiation or maintenance of access to health services and practitioners Targeting change in behaviour, existing and new	Active participation by person/patient Symptom management (Barlow et al. 2002) Generic versus illness-specific behavioural tasks Individual versus group tasks Medical and role management Self-regulation/self-monitoring Lifestyle change and education

<p>Self-management support</p>	<p>More focused and complex networks: patients, practitioners and the healthcare system          May require a refocus of health practitioner activity</p>	<p>Essential prerequisite          Service development and chronic disease management improvement, including the provision of self-management support, decision support, delivery system redesign, and clinical information systems          Development of new skills in practitioners (e.g. problem solving and goal setting), with the patient as a key resource          Patient empowerment, activation and education          Increasing self-management skills          Cognitive symptom management, positive changes in health behaviour, self-efficacy and health status and number of hospitalizations</p>	<p>Emphasizes collaboration between patient, healthcare practitioner and healthcare system, in standardized, programmatic interventions to improve self-management behaviour          Generic programmes, include the Chronic Disease Management Programme; Chronic Care Model; Expert Patient Programme          Disease-specific applications are seen in diabetes and heart failure</p>
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**Table 6.2** Overview of behavioural theories and related self-management support interventions

<i>Behavioural theory</i>	<i>Underlying concept</i>	<i>Related self-management support interventions</i>	<i>Key texts</i>
Rational choice theory	Humans seek to maximize their welfare within constraints and make decisions in line with stable preferences after weighing the expected costs and benefits of an action.	Information leaflets, educational interventions, financial incentives, patient decision aids	Mill and Bentham (1987); Hargreaves et al. (1992)
Theory of reasoned action, theory of planned behaviour attitude/social influence/self-efficacy model (ASE model)	Behavioural intention is the main determinant of human behaviour	Peer modelling, peer support	Fishbein and Ajzen (1975); Ajzen and Fishbein (1980); De Vries et al. (1988)
Self-regulation	The beliefs of individuals are important factors in how different people respond to their health and illness	Symptom awareness, self-monitoring, diaries	Leventhal et al. (1980, 1984)
Trans-theoretical model of change	Motivation and attitudes are important factors in behaviour change	Stages of change, social marketing	Prochaska and DiClemente (1983)
Social cognitive or social learning theory	Behaviour is influenced by outcome expectations, observational learning and self-efficacy expectations	Social marketing, peer modelling, goal setting and planning, self-belief/confidence building	Bandura (1977, 1997)
Stress-coping framework	People develop coping mechanisms in response to recurrent stressful situations that pose serious challenges to adaptation	Teach adaptive coping strategies, support groups, cognitive-behavioural therapy, education groups	Lazarus and Folkman (1984)
Self-determination theory	Three psychological needs must be met in order to motivate people to reach a particular health behaviour goal: autonomy, competence and relatedness to others	Collaborative care planning, personal goal setting, skill training	Deci and Ryan (1985)

## **BOX 6.1 EXAMPLES OF SELF-MANAGEMENT SUPPORT PROGRAMMES**

### **Chronic Disease Self-Management Program**

The Chronic Disease Self-Management Program (CDSMP) was developed at Stanford University (Lorig et al. 1999, 2001) and comprises a six-week session of workshops, with weekly sessions of two and a half hours that usually take place in community settings such as senior centres, churches, libraries and hospitals. People with different chronic conditions attend together. Workshops are facilitated by two trained leaders, one or both of whom are non-health professionals with a chronic illness themselves.

Subjects covered in the workshop include (1) techniques to deal with generic problems of chronic illness such as frustration, fatigue, pain and isolation; (2) appropriate exercise for maintaining and improving strength, flexibility and endurance; (3) appropriate use of medication; (4) communicating effectively with family, friends and health professionals; (5) nutrition; and (6) ways to evaluate new treatments. Each participant in the workshop receives a copy of the companion book, *Living a Healthy Life with Chronic Conditions*, and an audio relaxation tape, *Time for Healing*.

It has been claimed that the format in which the programme is taught accounts for its effectiveness. Classes are highly participative, where mutual support and success are used to build up the participants' confidence in their abilities to manage their health and maintain activities. CDSMP does not conflict with other interventions or medical treatment of patients. It is designed to enhance regular treatment and disease-specific education. It is especially helpful for patients with multiple chronic conditions and disability, as the programme focuses on the development of skills to coordinate the different tasks necessary to manage health and to keep an active life.

### **Comprehensive Health Enhancement Support System**

The Comprehensive Health Enhancement Support System (CHESS) is an interactive, computer-based system to support people with managing chronic conditions or other health-related crises or concerns (Gustafson et al. 2001). CHESS provides information, referral to service providers, support in making tough decisions and networking with experts and others facing the same concerns. CHESS is designed to improve access to health and human services for people who would otherwise face psychological, social, economic or geographic barriers to receiving services.

The system is accessed from a patient's home via the Internet or software installed on a personal computer. People participating in the CHESS project who do not have a computer are loaned one for up to a year. CHESS has also been installed in community centres, health centres, college dormitories and in the workplace. CHESS is currently being used by several major health organizations in the United States and Canada. CHESS has been successfully trialled with different target groups including the elderly, people with low education and people from minority populations.

People have used the facility equally although in different ways.

**Table 6.3** Level of inactivity among patients with at least one chronic disease by level of physical disability and income, 2005

	No.	Inactive (%)
<i>Disability</i>		
None/mild	1102	9
Moderate	450	20
Severe	167	52
Total	1719	
<i>Income (€)</i>		
<( 850	139	32
850–1450	775	29
1450–1900	435	18
1900–2300	296	18
2300–2700	176	14
2700–3300	184	14
>3300	126	8
Total	2131	

Source: Data of the National Panel of the Chronically ill and Disabled (NPCG, NIVEL), the Netherlands.

**Table 6.4** Knowledge about medication use in 440 patients with chronic obstructive pulmonary disease by educational level, 2006

<i>Educational level</i>	<i>Mean score (out of 11)</i>	<i>Standard deviation</i>
No education/primary school	3.3	2.6
Lower vocational	4.1	3.2
Intermediate vocational	4.2	2.9
Higher vocational/university	4.6	3.0

*P* for trend < 0.05.

Source: Data of the National Panel of the Chronically ill and Did (NPCG, NIVEL), the Netherlands.