



***National Institute for  
Health and Clinical Excellence***

A rapid review of the current state  
of knowledge regarding lay-led  
self-management of chronic illness

*Evidence review*

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*Michael Bury, Jennifer Newbould, David Taylor*

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# Foreword

The Health Development Agency (HDA) was established in 2000. Between then and 2005, when the functions of the HDA were transferred to the National Institute for Health and Clinical Excellence (NICE), the HDA helped to build the evidence base in public health with an emphasis on what works and a special focus on reducing inequalities in health.

The HDA had the task of mapping and synthesising the evidence across priority areas of public health. It developed a number of ways of taking a systematic approach to compiling the evidence, identifying gaps and making the evidence base accessible. The evidence briefing series was one of the ways in which the HDA Evidence Base was disseminated (full details of the process of developing the Evidence Base and the associated methodological activities can be found in Graham and Kelly 2004; Kelly et al. 2002, 2003, 2004; Killoran and Kelly 2004; Swann et al. 2005).

The necessity for reviewing reviews, or tertiary-level research, stems from the proliferation over the last decade, or more, of systematic and other types of review in medicine and public health. The HDA published a range of evidence briefings that cover:

- Teenage pregnancy and parenthood
- HIV prevention
- Prevention of sexually transmitted infections
- Management of obesity and overweight
- Ante- and post-natal home-visiting programmes
- Prevention of low birth weight
- Breastfeeding
- Accidental injuries in children and older people
- Public health interventions for increasing physical activity among adults
- Smoking and public health
- Drugs misuse

- Youth suicide prevention
- Health impact assessment
- Prevention and reduction of alcohol misuse
- Prevention and reduction of exposure to second-hand smoke
- Secondary interventions for chronic illness
- Housing.

Taken together, these briefings provide a comprehensive synthesis of the evidence drawn from review-level literature. They are available on the NICE website: [www.publichealth.nice.org.uk](http://www.publichealth.nice.org.uk)

These evidence briefings have been based on evidence drawn from systematic and other kinds of reviews. This means that the type of evidence that does not traditionally find its way into reviews has not been considered in detail for these documents.

In another HDA evidence series, evidence reviews, of which this is one, the scope of the coverage is extended to primary research, other kinds of evidence and other types of study. Evidence reviews are traditional reviews, overviews or syntheses of multiple evidence sources drawn from different research traditions. These take a variety of forms and formats (see for example the evidence reviews on drugs misuse prevention (Coomber et al. 2004a) and risky behaviour (Coomber et al. 2004b). In some cases evidence reviews consist of analyses of primary studies, drawn from the published and unpublished literature. In other cases they comprise summaries of the theoretical concepts and ideas that relate to the evidence base in public health. Overall, evidence reviews provide a general evidence resource on a range of public health topics.

This evidence review seeks primarily to clarify what is known about the impact of lay-led self-management

programmes for people with chronic illnesses. Other evidence reviews on transport, maternal and child nutrition, and worklessness and health are currently in preparation.

The construction of the HDA Evidence Base involved collaboration with a number of partners who have interests and expertise in practical and methodological matters concerning the drawing together of evidence and its dissemination. In particular the HDA acknowledged the following: the Centre for Reviews and Dissemination at the University of York; the EPPI-Centre at the Institute of Education at the University of London; Health Evidence Bulletins Wales; the ESRC UK Centre for Evidence Based Policy and Practice at Queen Mary College, University of London and its nodes at the City University London and the MRC Public Health Sciences Unit at the University of Glasgow; members of the Cochrane and Campbell collaborations; the United Kingdom and Ireland Public Health Evidence Group and the members of the Public Health Evidence Steering Group. This latter organisation acted as the overall guide for the HDA's evidence-building project. The cooperation of colleagues in these institutions and organisations has been of significant help in the general work in preparing the framework for how we assess the evidence.

Every effort has been made to be as accurate and up to date as possible in the preparation of this briefing. However, we would be very pleased to hear from readers who would like to comment on the content or on any matters relating to the accuracy of the briefing. We will make every effort to correct any matters of fact in subsequent editions. Comments can be made by using our website, [www.publichealth.nice.org.uk](http://www.publichealth.nice.org.uk)

**Professor Michael P Kelly**  
**Director, Centre for Public Health Excellence**  
**National Institute for Health and Clinical Excellence**

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**Michael Bury**, Emeritus Professor of Sociology, University of London

**Jennifer Newbould**, Research Fellow, School of Pharmacy, University of London

**David Taylor**, Professor of Pharmaceutical and public Health Policy, School of Pharmacy, University of London.

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# Introduction

In any area of human experience it can be taken as little more than a well worn cliché to say that we live in rapidly changing times. Nevertheless, the last century undoubtedly witnessed major transformations in the public health profiles and healthcare systems of many societies. The most important developments have been associated with demographic and epidemiological transition. These processes may now be regarded as near to completion in Western European countries such as the UK, although they are still underway globally (see, for example, Gray 2001; Taylor 1972; Taylor and Bloor 1994). The result is an older population and an increased prevalence of long-term health problems, together with low rates of mortality and morbidity caused by infectious illnesses in the child and working age populations.

Many diseases that were once life threatening are now controllable. A few, most notably smallpox, seem to have been eliminated altogether. But longer life expectancy has also – to date at least – brought in its wake a far greater probability that individuals will survive to experience significant proportions of their lives with conditions such as arthritis or atherosclerosis. Long-term mental health problems are also becoming more prominent on health service agendas across the world.

It is against this background that this rapid review presents an analysis of one aspect of this ongoing evolution – the growth of policy maker interest in lay-led self-management approaches to living with chronic illness.

Self-management is not new in the field of health and social care. Models of coping with adversity based on the virtues of self-help, self-reliance and family and community resilience were common in Victorian Britain, and many of today's practitioners and patients argue that they have long promoted 'self-management'. Conditions such as diabetes, asthma and epilepsy often require a

degree of self-medication and/or self-monitoring of biomedical variables, as well as attention to diet and other lifestyle factors.

However, commentators such as Gerhardt (1989) have argued that the modern use of the term 'management' in the context of chronic illness signals a 'social level' move away from a medical model of treatment or cure. Instead, increasing numbers of people may be seeking to act as empowered service users who wish to control their own approaches to living with illness with or without the help of medical practitioners and other professionals.

## The development of self-management as policy

In England and the other UK nations health policy has recently paid increasing attention to initiatives designed to support people with long-term chronic conditions. The 1999 white paper *Saving Lives: Our Healthier Nation* set out the then new Labour Government's public health strategy. Chapter 3 stated that 'people with long-term health problems such as diabetes, epilepsy or arthritis are skilled at recognising warning signs when their symptoms are getting worse' (Department of Health 1999).

Citing Arthritis Care programmes previously developed in both the USA and UK, *Saving Lives: Our Healthier Nation* concluded that 'trained staff and volunteers' were able to help people with arthritis take control of their lives, and make best use of professional advice. It was also announced that the CMO (Chief Medical Officer, Sir Liam Donaldson) had been asked to set up a task force to design a new Expert Patients Programme 'to address the needs of the very many people in this country with a chronic disease or disability, who amount to one in three of the total population'.

The following year saw further confirmation that promoting the self-management of chronic disorders is a priority in official British thinking about healthcare. *The NHS Plan* set out a vision in which the 'NHS will become a resource which people routinely use to help look after themselves' (Department of Health 2000). Progress in this direction was associated with other developments, such as the creation of NHS Direct. The formal establishment of the Expert Patients Programme (EPP) commenced in 2001 (Department of Health 2001). This initiative was in large part based on the work of Kate Lorig, head of the Chronic Disease Self Management Program (CDSMP) in California. Sir Liam stated in 2003 that 'nearly 10 million people' in England alone live with a chronic disease and that in the past the 'wisdom and experience' of the patient had only been tacitly acknowledged in medical circles (Donaldson 2003). The EPP was being designed to correct this imbalance, and was to be 'a centre piece of the NHS approach to chronic disease management in the 21st century'.

Lorig's approach would offer 'a more radical and innovative solution' to resolving the challenges associated with chronic disease (Donaldson 2003). The CMO made clear his concern to improve the quality of life experienced by people with chronic illnesses, claiming that 'self-efficacy predicts a healthier lifestyle'. He also reinforced the idea that 'partnership' between patients and healthcare providers is a central concern. 'The patient as expert and partner in care is an idea whose time has come and has the potential to create a new generation of patients who are empowered to take action to improve their health in an unprecedented way' (Donaldson 2003).

Subsequently, as the pilot phase of the EPP was implemented, the theme of chronic illness management was further emphasised in a number of other policy statements. For instance, *The NHS Improvement Plan* (Department of Health 2004) devoted a chapter to the topic of supporting people with long-term conditions. This began with the eye catching statement that 'about 60% of adults report some form of long-term chronic health problem', and then offered a model for tackling what might appear to be a potentially overwhelming problem.

At the top level, 'case management' for those with complex multiple problems was seen as the most appropriate modality. A new form of specialist clinician was envisaged. *The NHS Improvement Plan* announced

that over 3000 community matrons would be introduced into the NHS by 2008 to deliver 'case management' to some 250,000 patients with complex needs. Although some recent commentaries have cast doubt on the feasibility and effectiveness of this proposal (Hutt et al. 2004; Roland et al. 2005), other observers and policy contributors have seen a positive role for such an approach (Ham et al. 2003; Wilson et al. 2005). It is currently expected that a new white paper will be published in late 2005 or early 2006 that will address the topic of developing community matron-led services in the wider context of promoting plurality and competition in primary care.

At the second level of care, the model described in *The NHS Improvement Plan* offered 'disease management' for those with specific conditions such as diabetes or heart disease. It noted that the National Service Frameworks are setting the standards of care to be provided for NHS patients with these conditions and that the 2004 General Practice contract will incentivise doctors and nurses to deliver the most effective care. The Plan also emphasised that the use of effective drugs alongside other forms of treatment will be of vital importance. For example, it stated that 'it has been estimated that drugs for cholesterol alone have saved up to 7000 lives'.

Below this, at the third level of care, individuals with long-term conditions will be helped by self-management programmes. This bottom level of support will be available to 70-80% of the overall patient population. *The NHS Improvement Plan* explained that through 'using trained non-medical leaders as educators, people with arthritis and other long-term conditions have been equipped with the skills to manage their own conditions. Compared with other patients, 'expert patients' report that their health is better, and that they cope better with fatigue, feel less limited in what they can do and are less dependent on hospital care' (Department of Health 2004).

A more recent paper, *Self Care – A Real Choice* (Department of Health 2005a), has similarly argued that there is 'growing evidence' that supporting self-care can help to improve health and quality of life, leading to an increase in patient satisfaction and a reduction in the use of formal services. This last objective has now become embodied in a specific target, a reduction of inpatient emergency bed days by 5% by March 2008 (*Supporting People with Long-term Conditions*, Department of Health 2005b).

So by the middle of 2005 lay-led self-management was being seen as a major component of health policy in Britain, and said to be supported by a growing body of evidence on its effectiveness.

## Scope of this review

A number of forces may be helping to promote policies on self-care and support for official and independent lay-led self-management initiatives such as the Expert Patients Programme. This review seeks primarily to clarify what is known about the impact of lay-led self-management programmes for people with chronic illnesses. But a number of related areas are also touched on. Although the main focus of this report is on specific 'lay-led' interventions developed by Kate Lorig and her collaborators in the USA and in the context of the Expert Patients Programme in the UK, sociological and allied studies on wider aspects of chronic illness management in the community (and on interventions which are not strictly speaking 'lay-led') have also been analysed.

Two other introductory points should be made. The first concerns the size and character of the public health problem constituted by chronic illness. In many of the policy documents referred to previously it is taken as given that chronic illness is widespread and increasing in our community. This assumption needs to be treated with a degree of caution. For instance, despite population ageing it is possible that new cohorts entering later life are bringing with them 'healthier' past profiles. This may in time lead to 'the compression of morbidity': that is, the postponement of illness to the last years of life (Fries 1980, 1989; Manton and Gu 2001).

It should also be recognised that many of the figures used in the estimates of chronic illness prevalence are based on self-reports. Many commentators have argued that these can be misleading. Reports of subjective distress may be significantly higher than objective measures (Heath 2005; Sen 2002). However, it can also be said that on occasion older people and others may underestimate their health problems, treating as normal conditions that actually compromise their health (Gooberman-Hill et al. 2003).

A second set of caveats concerns the question of how to evaluate the self-management of chronic illness, and the impact of interventions intended to promote self-

management. Issues such as research design, methods, analysis and outcomes are large subjects in their own right, fraught with difficulties and differences of expert opinion. For example, even claiming that a programme or initiative is 'effective' carries many different connotations in lay, medical and research communities. For some commentators only the accumulation of carefully conducted randomised controlled trials (RCTs) can adequately support such a view, while others argue that RCTs and similar studies typically produce evidence about the *efficacy* of an intervention among trial participants rather than its *effectiveness* in routine practice. Similarly, for some researchers, a patient's expressed satisfaction with an intervention is an important indicator of effectiveness, while for others such measures are intrinsically suspect.

This rapid review seeks only to provide a guide to the current evidence base rather than a full evaluation.

# Methodology

Literature concerned with the current state of knowledge regarding lay-led management of chronic illness was identified in two main ways: searching of peer reviewed journals and the identification of 'grey' literature. Both approaches are outlined in this section.

## Searching of peer reviewed journals

Searches were conducted with use of the following search engines:

- BMJ.com
- MEDLINE
- PsycLIT
- ScienceDirect.

The following search terms were used.

- Chronic condition (used in conjunction with other terms)
- Chronic disease (used in conjunction with other terms)
- Chronic illness (used in conjunction with other terms)
- Concordance
- Consumers in healthcare
- Empowerment
- Expert Patient Programme
- Lay-led self-management
- Long-term ill health
- Medicine/s management
- Partnership in healthcare
- Patient/professional relationships
- Self-care
- Self-efficacy
- Self-management.

The names of key authors/academic institutions in the field of lay-led self-management were also searched for:

- Barlow J
- Kennedy A
- Lorig K
- Rogers A
- Sobel D
- Stanford University
- University of Manchester.

Relevant articles from reference lists of other articles were retrieved and subsequently reviewed. In particular, for the sociological section of this review hand searches of the journals *Sociology of Health and Illness* and *Social Science and Medicine* were also conducted for relevant articles, published from 1990 onwards. The details of over 300,000 articles were identified through the search processes outlined above. From these, article titles were first scanned and then a sub-set of abstracts were read to ascertain if the article referred to the lay-led management of chronic illness. After these exercises were completed, 44 articles were deemed relevant and the full article obtained. On further examination 17 articles and two conference reports were judged to meet in full the criteria for the search and were included in this rapid review. That is:

- they were in English
- they were published in or after 1960
- they related entirely or in part to lay-led self-management interventions.

The remaining articles (some of which are referred to briefly in this review) were:

- 15 commentary or opinion papers regarding lay-led management
- 3 review papers
- 7 studies of interventions led by healthcare professionals (obtained because information was not clear from the abstract or title).

## Identifying 'grey' literature

The search process also intended to identify research and commentaries concerned with the lay-led management of chronic illness not published in peer reviewed journals.

The following websites were examined:

- Arthritis Care ([www.arthritiscare.org.uk](http://www.arthritiscare.org.uk))
- Chronic Disease Self-Management Programme ([www.patienteducation.stanford.edu/programs/cdsmp.html](http://www.patienteducation.stanford.edu/programs/cdsmp.html))
- Expert Patients Programme ([www.expertpatients.nhs.uk](http://www.expertpatients.nhs.uk))
- Long-term Medical Conditions Alliance ([www.lmca.org.uk](http://www.lmca.org.uk))
- National Primary Care Research and Development Centre ([www.npcrdc.man.ac.uk](http://www.npcrdc.man.ac.uk)).

Searches of these websites provided unpublished opinion, comment and research concerning the lay-led management of chronic illness. The websites also provided links to further 'grey' literature such as conference papers and patient testimonials. The authors are grateful to all those individuals who also provided relevant information on a confidential basis.

The table shown in the Appendix details the key articles identified on lay-led self-management of chronic conditions. However, the degree to which interventions were in fact led by 'lay' tutors varied between interventions. The final column of the table therefore reports the extent to which interventions were led totally by lay persons, or by lay persons in conjunction with healthcare professionals. Later sections of this review focus in greater detail on the studies identified in the Appendix, concentrating on those most often cited as providing positive evidence for the use of lay-led self-management programmes.

# Sociological study of illness

The dividing line between sociology and social psychology in exploring illness experience is not always clearly defined. This can on occasions lead to potentially avoidable conflicts in the interpretation of evidence on the value of interventions. Both disciplines deal with human understanding and behaviour. The differences between them lie in the scope and focus of their enquiries. Sociology is fundamentally concerned with what might be described as the externally observable or structural determinants of health. These can be material in nature, or contained in the cultural and social systems that surround individual perceptions and interactions. Social psychology is concerned with cognitive and other processes at the level of the individual, and interactions between individuals observed at a cognitive level.

Sociological debates about the pattern of chronic illness (by such factors as class, gender and ethnicity) relate to epidemiologically significant variables (such as the occurrence of illness and its distribution in the community, especially by age). However, much of the research in the field of illness experience has involved qualitative rather than quantitative studies of social processes and the experienced realities of everyday life. These social processes have a direct bearing on self-management and self-care issues. The discussion below presents key examples from the sociological literature on chronic illness, and particularly those papers that have had a seminal influence on this field (see also Armstrong 2003).

## From Parsons to Strauss

### Parsons – the sick role (1951)

From the 1950s to the 1970s medical sociology was strongly influenced by Talcott Parsons' concept of the 'sick role', first formulated in *The Social System* (Parsons

1951). The sick role was envisaged as an 'ideal type' temporary role, appropriately adopted by an individual when ill. The sick person was allowed exemption from the performance of normal social roles and obligations (such as work) and was exempt from being responsible for their own state of health. At the same time the sick person was expected to try to get well as quickly as possible and to seek help from and cooperate with medical experts.

Several critiques of Parsons' work pointed out that chronic illness does not fit this 'acute' pattern (Gallagher 1976). Parsons later responded that a form of 'impairment role' (Gordon 1966) often exists in chronic illness, where the individual meets expectations to 'maintain as many activities of life', if not fully recovering (Parsons 1978, p19). In the case of chronic conditions he noted that individuals may become better informed about their experiences and challenges, and ultimately know as much if not more about their illness than the healthcare professionals who treat them.

The echoes of such ideas can be heard in contemporary lay-led self-management programmes. From the time of Parsons' sick role onwards, it was clear that the nature of chronic illness needed specific attention. In the subsequent substantial sociological literature on the subject, conditions such as heart disease, multiple sclerosis, arthritis, diabetes, asthma and epilepsy were studied.

### Glaser and Strauss – trajectory frameworks (1965)

In reaction to Parsons, sociologists focusing more on social interaction, such as Glaser and Strauss, outlined a 'trajectory' framework for understanding illness (though it was first used in the study of dying – Glaser and Strauss 1965). Chronic illness was seen as an experience in which

the individual passes through a series of stages, dependent on their condition, at times improving and at times getting worse.

Strauss (1973) stressed that dealing with chronic illness was not simply a medical issue but a social one. He listed family disruption, marital stress, role disruption, and adjustment and stigmatisation as related 'social problems of chronic illness'. Strauss acknowledged the importance of the role of healthcare professionals but saw them as neither the focal point of, nor a primary element in, living with a chronic illness. He identified the multiple problems of living with a chronic condition as:

- managing medical crises (that may even lead to death)
- managing treatment regimens
- controlling symptoms
- organising one's time efficiently
- preventing or living with social isolation
- adjusting to worsening or improving of the condition
- normalising interaction and life, despite the disease.

Strauss's approach directly influenced later self-management programmes (Lorig 2002), in which specific 'tasks' were identified for patients to undertake 'successfully' or otherwise.

**Strauss – *Chronic Illness and Quality of Life* (1975), Corbin and Strauss – *Managing chronic illness* (1985), *Unending Work and Care* (1988)**

This body of research developed ideas from Strauss's key 1973 paper, discussed above. Based on several studies carried out in California among people with conditions such as arthritis and emphysema, the 1975 collection of papers highlighted the steps needing to be taken to live as 'normal'. Social processes rather than a uniform set of experiences were emphasised. In this contextualised approach to chronic illness Corbin and Strauss (1985, 1988) identified three lines of 'work' that lay people with chronic illnesses must normally undertake:

- **illness work** – symptom management, diagnostic related work and crisis prevention and management
- **everyday life work** – daily work tasks that need to be done eg – housework, looking after children, paid work (employment), eating and self-care
- **biographical work** – reconstruction of the ill person's biography.

This approach raised the importance of the family, in particular, in supporting the 'work' involved at these three levels. Such work may be done by the person who is chronically ill, or by family members (often their spouse).

**Bury – *Biographical disruption* (1982), *Meanings at risk* (1988), *Research and prospects* (1991)**

In the UK, Bury took up some of the insights offered by Strauss in a study of rheumatoid arthritis. He developed a framework that emphasised the impact of chronic illness on the biography of the individual. This work examined 'disruptions of social relationships and the ability to mobilise material resources' among the chronically ill. It documented the 'before and after' character of life with a chronic illness, and dealt with three main stages of illness experience:

- onset, and problems of explanation and legitimation
- the impact of treatment
- the development of adaptive resources.

The latter process, in turn, was itself seen to involve three dimensions:

- **coping** – the psychological process of learning how to tolerate the effects of illness and maintain a sense of self-worth
- **strategy** – the actions people take to mitigate the effects of illness
- **style** – the way people respond to their illness and treatment regimens, for example by withdrawing from social interaction or making the illness a more visible part of their identity.

Like Corbin and Strauss, Bury emphasised the contexts in which the meaning of illness are negotiated, especially that of the family. Williams (1984) also stressed the importance of achieving continuity across biographical time through a process of 'narrative reconstruction', where sense is made of the illness – and wider meaning restored – against the backdrop of the individual's social and personal history. Other studies have added to our understanding of the centrality of family processes in managing chronic illness (Anderson 1988; Canam 1993; Jobling 1998).

## The sense of self, and links between the body and identity in illness

During the 1980s and 1990s several other key studies examined how chronic (in most research physical, as opposed to severe mental) illness can alter an individual's self-image. They also made connection with the emerging interest in the sociology of the body.

### Selfhood and the sociology of the body

Charmaz – *Loss of self (1983), Good Days, Bad Days (1993), Experiencing chronic illness (2000)*; Kelly and Field – *Chronic illness and the body (1996)*

Charmaz's work was based on in-depth interviews (n = 73) with chronically ill people (Charmaz 1983). Participants had various chronic conditions, including cardiovascular disease, diabetes, cancer and multiple sclerosis. Charmaz took the view that chronic illness was not merely about the experience of physical suffering but also about the challenge to an individual's self-identity, seen as a product of an individual's interaction with others. In her study, those with chronic conditions were concerned about the type of person they were becoming and felt they had lost their former self-image as the result of the onset of the condition. From this 'loss to self' there emerge four dilemmas:

- living a restricted life
- experiencing social isolation, and also attempting to form more intense relationships with others that may backfire
- being discredited as the result of interactions with others and from the unmet personal expectations of the ill person
- burdening others, especially as the result of increasing disability and need for care.

Charmaz's later work stressed the way in which individuals, in tackling these problems, may 'transcend the loss' and integrate the self on a 'new level' (Charmaz 2000, p287). Similar ideas emphasising remission and restitution have been discussed by Frank (1991, 1995). [In the context of mental ill health, earlier writers such as Laing (1960, 1967) worked to develop understandings of the ways in which long-term mental impairments and disabilities and associated social handicaps can redefine an individual's sense of self and their social positioning. But his work – and that of other commentators on the sociology of chronic psychiatric illness (see, for example, Goffman 1961, Scheff 1972) – is arguably distinct from the main body of literature described here.]

### Kelly and Field – Chronic illness and the body (1996)

Kelly and Field's paper suggested how the body might be integrated into sociological accounts of the experience of chronic illness. The body itself is viewed by Kelly and Field as the central link between 'self-identity' and wider society. Self and identity are core aspects of everyday experience which the onset of chronic illness and changes in bodily function affect. In normal circumstances the body is largely taken for granted, but when the body 'malfunctions' the relationship between self and society is disrupted. This reveals the way that 'cultural competence' is based on bodily performance, and that this becomes a more conscious and deliberate project in the face of illness onset. The potential for stigma in chronic illness, noted by a number of researchers (Gray 2002, Scambler and Hopkins 1986), stems in large part from difficulties in maintaining such competence in everyday interaction.

## Recent studies and reviews

Several more recent essays and reports of empirical work have provided critical reflections on many of the studies and ideas briefly summarised above. In particular, the idea that chronic illness is best regarded as a disruptive event (either in terms of the individual's biography or of their social relationships) is not always self-evident. For example, Sanders et al. (2002) interviewed 27 sufferers of osteoarthritis, with a median age of 76, and found that though most symptoms were experienced as disruptive, they were also seen as an integral part of the person's biography. These accounts suggested that not only does age make a difference to chronic illness perception, but so too does the type of illness and its relationship to the individual's identity. However, 'playing down' the nature of such symptoms may be double-edged – helping to reduce the salience of symptoms but leaving the need for treatment and care unmet.

Similarly, Pound et al. (1998) found in a study of stroke 'victims' that the accepted view of the condition as a dramatic event, a 'bolt from the blue', was not always borne out. In interviews with a sample of 40 patients with a mean age of 71 it was found that social circumstances and, again, age acted as important mediators of illness experience. Where older people live in poor circumstances it is likely that a stroke (or possibly onset of other chronic conditions) will be seen to be yet another problem to be dealt with, rather than a shattering 'before and after' event.

By describing stroke as 'not that bad' respondents in this study drew attention to the serious difficulties faced elsewhere in their lives, especially 'desperate need of money, adequate housing, aids and adaptations, domiciliary services and information' (Pound et al. 1998). In a more general overview Williams (2000) has emphasised the continuity as well as discontinuity found in lay people's biographies in the face of the onset of chronic illness. Following researchers such as Pound, he also argues that links between chronic illness onset and social inequalities need to be systematically studied. Without this, 'sociological' views may tend towards overly individualistic perspectives. Lawton (2003) has also drawn attention to issues such as the role of the caregiver as an important dimension of sociological study.

The research summarised above has been largely qualitative in nature, exploring the range of meanings attached to chronic illness experience and contextualising them in everyday settings. Armstrong (2003) has noted that this body of work has produced a remarkably homogeneous set of concepts, dealing variously with continuity and discontinuity across the lifecourse. Armstrong also highlights the 'threat to identity' theme present in this literature. This field of study brings sociological work into close proximity with social psychology.

Most recently, attempts have been made to synthesise qualitative research findings on chronic illness to strengthen claims to validity in the field. Perhaps the most successful example is that of Campbell and colleagues (2003). Developing what they call a 'meta-ethnography', these authors examine a range of studies on diabetes and diabetes care. Beginning with a paper by Kelleher (1988) on strategies for managing diabetes (followed later by a study on the role of self-help groups – Kelleher 2005) Campbell et al. were able to synthesise typologies of patient responses found in four of the seven studies considered. They then went on to identify a number of key concepts from the seven studies, dealing with the way in which patients achieved a balance between the disorder and a sense of wellbeing and control. These included:

- trust in self
- less subservient approaches to healthcare providers
- strategic non-compliance with medication programmes
- acknowledgement that diabetes is a serious condition.

In this way it was possible to build up a consistent picture of the complexity of everyday chronic illness management from otherwise unconnected studies.

## Implications for chronic illness self-management

- Over the last 30 years sociological studies, mainly qualitative in character, have documented the active steps lay people take in managing chronic illness in everyday settings. This literature confirms that regardless of recent policy led initiatives, the self-management of chronic illnesses is already established, extensive and sophisticated in the community.
- The experience and management of chronic illness is influenced by immediate social factors (the demands of social interaction); everyday settings and environments (for example the availability and character of family and community support); and the wider social determinants of health and illness (in particular, age and social class). It will be important not to lose sight of the latter two domains while seeking to improve support for individuals at the psychological level.
- A contextual approach to chronic illness management has involved the exploration of continuity as well as disruption in lay people's lives, and a recognition of the delicate mechanisms often involved in maintaining viable social roles and satisfactory identities.
- Sociological research has emphasised that while common problems can be identified among the chronically ill, much depends on the social circumstances of the individual: chronic illness does not present a uniform set of problems inviting a uniform response. Research in this area has described the plurality of what people with chronic illnesses do to live with their conditions, rather than providing a single prescription for what they *should* do.

In conclusion, healthcare responses and interventions need to be based on a careful assessment of the different needs of chronically ill individuals. These vary with age, social circumstances, medical conditions and/or existing self-management strategies. The transformation of empirically derived insights into normative guidelines for self or externally mediated disease management approaches should be treated with some caution.

# Studies of lay-led self-management programmes

Living with a chronic illness can be viewed as a socially, as distinct from a medically, defined experience. This lived experience of illness is far removed from a conventional biomedical model of illness. It also challenges assumptions (not least by managers and others seeking to drive 'improved' performance) about the role of healthcare professionals in this area. Given this, it is not surprising that lay-led self-management programmes have emerged.

The focus of the self-management approach is on enabling the sufferers of chronic illnesses to gain motivation and/or skills needed to improve their conditions' management. These programmes are different from traditional interventions in which participants receive medical advice and information about their condition from healthcare professionals. This, it may be suggested, is not only because of the 'unqualified' credentials of their leaders, but also because of the basic nature of their approach to specific forms of illness and chronic illness generally. Many, if not all advocates of lay-led self-management programmes argue that their key function is to promote a sense of confidence or 'self-efficacy' in dealing with illness and its effects, rather than to impart technical knowledge or specific disease management skills (Jones R, personal communication, 2005). However, confident and 'empowered' individuals should arguably be more able to acquire and use such skills than those with low self-efficacy.

## Condition-specific lay-led self-management programmes

The first lay-led self-management programmes were condition specific and evaluations of them employed outcome measures related to the condition concerned. In a review of such disease specific self-management approaches, Barlow et al. (2002) noted that the format of

self-management interventions varied greatly, depending on which condition they were designed for. For example, arthritis programmes focused on a multi-component and holistic approach, whereas those for diabetes were more typically focused on blood glucose monitoring, problem solving, diet and exercise. Outcome measures were also condition specific: for instance, arthritis programmes normally focused on pain and physical functioning while those for people with asthma concentrated more on measures of peak air flow (Barlow et al. 2002).

In a recent review of RCTs of self-management interventions Newman et al. (2004) identified 62 studies relevant to three specific conditions (type 2 diabetes, arthritis and asthma). Sixty of these interventions were run by healthcare professionals: only three were lay-led self-management programmes. This review also found that the development of condition-specific lay-led self-management programmes has to date been very limited. (There is also considerable uncertainty as to the mechanisms involved in generating benefit from self-management programmes – see Chodosh et al. 2005.) The great majority of such interventions are still led by healthcare professionals, and are sometimes referred to as 'guided self-management' (Kennedy et al. 2003; Robinson et al. 2001).

### *Arthritis self-management programmes*

The first published papers dealing with lay-led self-management programmes were on arthritis care. The majority identified in this rapid review concerned arthritis self-management (see Appendix) and reported findings associated with the use of the Arthritis Self-Management Program (ASMP), designed in the USA by Kate Lorig and her colleagues at Stanford University. A key idea behind the ASMP was the use of lay leaders as tutors rather than healthcare professionals.

This emerged from early work (Lorig et al. 1986) comparing an intervention (using defined materials and course work exercises) delivered by lay leaders (n = 34) with the same course delivered by professionals (n = 34). This study also included a control group (n = 32). Questionnaires were self-completed by participants at baseline and after 4 months. At 4 months participants in both the lay-led and professional-led groups showed increases in knowledge and practice of exercise, as measured against their own group baselines. The lay-led group also indicated increases in relaxation and decreases in disability. There were no significant changes in the control group.

Comparing the groups, over a 4 month period the professional-led group had a greater increase in knowledge ( $p < 0.05$ ). But participants from the lay-led group reported greater practice of relaxation ( $p < 0.05$ ). No other significant differences between the two groups were found. Lorig et al. (1986) concluded that there was little difference in outcome terms between the intervention taught by lay leaders or professional leaders. They highlighted, however, the financial benefits deriving from the use of lay leaders. They estimated cost savings of between \$40 and \$600 per course using lay rather than professional tutors, with – as already noted – comparable results for participants.

Lorig continued to explore the benefits of the ASMP for participants. Attention also began to focus on the length of time participants benefited from the effects of the ASMP. Lorig et al. (1993) recruited participants who had completed the ASMP 4 years previously (n = 224). No formal control group was used, but a comparison group was selected from a population of participants who, over the same period, had taken part in either a study of health system performance in the community or a separate observational study.

Self-administered questionnaires were completed at baseline and at 4 years by both groups. The findings appeared 'so dramatic' that the study was completed in a second group of participants who had completed the ASMP (n = 177), with the same results. In both groups that had completed the ASMP there was a 15-20% decrease in pain levels reported, sustained over the 4 year period, and the number of visits to physicians was also below the baseline level at 4 years. 'Self-efficacy' (see Bandura 1986, 1994) rose from baseline, despite a worsening in the level of disability. Lorig et al. (1993)

highlighted the financial savings of the ASMP across the 4 year period. However, despite the positive results reported in this study, its lack of a control group makes direct comparisons between the two groups difficult to interpret.

The ASMP has also been researched in the UK. Barlow et al. (2000) conducted an RCT of the programme. The total study sample included 544 participants, allocated to either an intervention group (n = 311, participated immediately in the ASMP) or a control group (n = 233, participated in the ASMP 4 months later). Courses consisted of six weekly sessions lasting approximately 2 hours, delivered by pairs of lay leaders. Topics covered in the ASMP include 'information about arthritis, an overview of self-management principles, exercise, cognitive symptom management, dealing with depression, nutrition, communication with healthcare professionals and contracting' (Barlow et al. 2000).

Participants were given a handbook as a guide through the course. Data were collected by a postal questionnaire completed by participants. The intervention group's members were accessed at baseline, 4 months and 12 months; the control group at baseline and 4 months. In addition, a sub-sample completed EQ-5D, an instrument used to assess health status (see [www.euroqol.org](http://www.euroqol.org)). This covers five domains – mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

From baseline to 4 months statistically significant differences in the intervention group compared with the control group were reported. For example, changes in depression and positive mood occurred, with a larger decrease in depression ( $p < 0.0005$ ) and higher degree of positive mood ( $p = 0.005$ ) in the intervention group. Changes were also identified within the intervention group at 4 months compared with its own baseline. Significantly more participants carried out relaxation ( $p < 0.0005$ ), flexibility exercises ( $p < 0.0005$ ) and strengthening exercises ( $p < 0.0005$ ). No significant changes were found in the control group in this period.

The sub-group who completed the EuroQol measure reported no significant improvement at 4 months from baseline in any of the five domains. This finding is surprising given the improvements in other outcome measures identified over this time period and the similarity of some items in both measures. For example, a

reduction in pain was reported at 4 months from baseline ( $p = 0.0005$ ) in the intervention group, yet no statistically significant changes were found in the pain/discomfort domain of EQ-5D.

The intervention group was followed up at 12 months from baseline, without controls. At this point similar improvements were found to those reported at 4 months. That is, statistically significant mean increases were found in arthritis self-efficacy, cognitive symptom management, communication with physicians and daily fluid intake. As at 4 months from their baseline, there were also increases reported in physical activity, relaxation ( $p < 0.0005$ ), flexibility exercises ( $p < 0.005$ ) and strengthening exercises ( $p = 0.001$ ), together with statistically significant mean decreases in fatigue, pain, anxiety and depression. In addition, there was found to be an increased positive mood and fewer mean number of visits to the GP to discuss arthritis. ( $p < 0.0005$  for all variables). These findings would seem to indicate the effects of participation in the ASMP were still evident at 1 year, albeit that the lack of an adequate control means that this finding is not fully confirmed by this (or any other available) study.

A more recent study by Lorig et al. (2004) compared use of the ASMP lay-led approach with a mail delivered, recipient tailored self-management intervention, SMART (Self-Management Arthritis Relief Therapy). SMART is an intervention tailored to the specific diagnosis, demographics, health status, medication, self-efficacy and other personal features of the participant. From a one page questionnaire, participant-specific responses are generated by computer. Subjects receive a personal letter from their physician, a summary report and a suggested plan of action. Participants also receive a handbook and quarterly follow-up materials. Follow-up information includes a second book, a relaxation tape and a leaflet on physician/patient communication. This sequence of information is repeated every 4 months for 1 year.

Findings from two RCTs were reported by Lorig et al. (2004). The first ( $n = 1090$ ) compared participants randomised to SMART ( $n = 522$ ) with participants receiving usual care ( $n = 568$ ). The second study ( $n = 341$ ) randomised participants to either the SMART cohort ( $n = 180$ ) or an ASMP group ( $n = 161$ ). Results were assessed at 1, 2 and 4 years, gathered via questionnaires that were self-completed by all participants every 6 months.

In the first study, SMART participants reported at 1 year improvements in disability, role function and self-efficacy, as compared with the usual-care group (for all variables  $p < 0.05$ ). Other differences between the groups were not statistically significant. At 2 years SMART participants reported lower disease severity than the usual-care group members, better role function and higher self-efficacy (for all variables  $p < 0.05$ ). The SMART group also reported fewer visits to rheumatologists and fewer total physician visits. However, at 3 years there were no longer any statistically significant differences between the usual care and SMART participants.

The second study, a comparison of the ASMP and SMART groups, also contrasted drop-out rates from each programme. Participants of the ASMP had a mean attendance of 4.6 sessions (total number of possible sessions was six). Thirty per cent of those who were assigned to the ASMP did not participate, compared with 12% of those assigned to SMART. At 1 year, SMART participants demonstrated improved self-efficacy ( $p < 0.01$ ) and disability ( $p = 0.02$ ). There were no other significant differences. At 2 years there were no statistically significant differences.

At 3 years the ASMP participants demonstrated greater improvements in global severity ( $p = 0.05$ ) and reduced number of physician visits, whereas there was a small increase in the number of physician visits with SMART participants. Lorig et al. (2004) concluded that use of the SMART programme could provide a cost-effective way to improve health status and reduce healthcare utilisation for up to 2 years. In the USA, in addition to their development of SMART, Lorig and colleagues are also involved in the development of an Internet online version of the Chronic Disease Self-Management Program (CDSMP) (Sobel et al. 2002 – see p13).

The findings of the 2004 SMART study can broadly be taken to indicate that a non-lay-led intervention provides comparable results with a lay-led intervention. If this is true in the long term it questions the fundamental principle of lay-led self-management, specifically the assumption that participants benefit from their tutors being lay leaders, or patient 'experts'. The mechanisms suggested for such possible gains relate to the power that patients/lay facilitators may have to act as role models and the possibility that personal interactions between lay peers avoid the infantilising risks associated with some forms of professional/patient interaction. Further, it is suggested

that messages transmitted via peers are more credible, or otherwise have a higher possible capacity to promote a sense of mastery among course participants – and the broader social positioning of lay-led groups influences the experiences and outcomes enjoyed by participants.

The success of SMART could be taken to indicate that it is the intervention itself, rather than the influence of lay group leaders, that is the main source of benefit. This point has been made by Weingarten et al. (2002) in a review of disease management programmes for people with a chronic illness. They found improvements in providers' adherence to guidelines and patient disease control across a range of type and style of interventions (n = 118), and in a number of conditions. The success of these wide-ranging 'patient-based' interventions in producing positive outcomes suggests that participation may be more important than the nature of any particular programme. One possibility is that putting oneself forward to participate in any intervention may predispose the individual to expect a desired outcome.

It may also be, of course, that persons who volunteer for self-management courses are already predisposed to be more active in self-management than those who do not. In any event, Weingarten et al. (2002) argue that evaluations in this area need to compare different types of intervention. Otherwise, there is a danger of falsely assuming that one particular approach – in this case lay-led group facilitation – has benefits over others, such as professionally facilitated patient support.

### **Other disease-specific lay-led self-management programmes**

Published studies of lay-led management have been dominated by evaluation of the ASMP. It has been adopted in several countries (USA, UK, The Netherlands, Australia and Canada) and adapted for Spanish speakers. Condition-specific lay-led self-management programmes for conditions other than arthritis are in earlier stages of development.

However, Lorig and Battersby (2003) reported findings from an Internet-based back pain programme in America. Participants (n = 422) were after 1 year found to have experienced improvements in disability, health distress, role function and self-efficacy. The treatment group had 63% fewer back-related physician visits at 1 year compared with 34% fewer visits in the control group (p = 0.07). A similar

programme to the ASMP has also been developed for those with HIV, the Positive Self-Management Program for HIV (PSMP). This involves 2.5 hour sessions once a week for 7 weeks in a community setting led by two lay tutors, one of whom has HIV (Stanford University 2005).

### **Generic lay-led self-management programmes in the USA**

Following the development of the ASMP, Kate Lorig and Halsted Holman worked with David Sobel, Director of Health Education at Kaiser Permanente, during the 1990s to develop a Chronic Disease Self-Management Program (CDSMP), to provide generic self-management courses (Sobel et al. 2002). The development of the new programme involved participants of varied ages and with a range of primary and comorbid conditions.

The CDSMP was based on three underlying assumptions:

- patients with different chronic diseases have similar self-management problems and disease-related tasks
- patients can learn to take responsibility for the day-to-day management of their disease(s)
- confident, knowledgeable patients practising self-management will use fewer healthcare resources.

The CDSMP, as originally designed, offered seven sessions of 2.5 hours a week. Each course had between 10 and 15 participants. It included material on:

- adoption of exercise programmes
- use of cognitive symptom management techniques
- nutritional change
- fatigue and sleep management
- use of medications and community resources
- managing the emotions of fear, anger and depression
- training in communication with health professionals and others
- health-related problem solving and decision-making.

A guide was also given to participants. Each CDSMP course was intended to be taught by a pair of trained volunteer lay leaders, although in fact 23% were health professionals and 15% were described as students, who may themselves not have had a chronic illness.

Lorig et al. (1999) conducted a 6 month RCT of the CDSMP. Eligible participants (n = 1140) were 40 years of

age or over and had a physician-confirmed diagnosis of either heart disease, lung disease, stroke or arthritis. Some also had an additional comorbid condition. Participants completed self-administered questionnaires at baseline and at 6 months.

The analysis compared the 6 month outcomes of the treatment group (n = 664, received CDSMP) with a control group (n = 476, members of which received CDSMP 6 months later). Compared with the control, the treatment group demonstrated significant improvement in 11 of the 15 outcome variables. These included disability (p = 0.002); social/role activities limitation (p = 0.0007); self-rated health (p = 0.02). Yet it is puzzling that despite such positive outcomes there was no significant improvement in reported levels of pain/discomfort and psychological wellbeing (p = 0.10). The latter is of particular concern. Within the framework of Lorig's overall research contribution it is difficult to see why psychological wellbeing should not have improved in the presence of higher levels of self-efficacy.

Lorig et al. (1999) also examined the data from each of the four condition groups independently. That is, they conducted discrete analyses relating to participants with arthritis, heart disease, lung disease and those with comorbidities. Their examination of 6 month change data revealed similar effects across all four diagnostic subgroups, although the generic outcome measures used across all four disease groups in this study demand attention. It is questionable whether some are applicable to all conditions. For example, the relevance of 'shortness of breath' in participants with arthritis might be queried.

Although in this study those in the treatment group reduced their visits to physicians slightly more than those in the control group, this difference was not statistically significant. However, differences in the recorded decreases in the number of hospitalisations and the number of nights in hospital were significant (p < 0.05). Lorig et al. (1999) pointed to the effect of this on costs, noting that the 6 month healthcare costs of each control participant were \$820 greater than for the treatment group (given an assumed cost of \$1000 a day per hospitalisation). That is, the treatment group members each experienced on average 0.8 of a day's hospitalisation during an overall time span of just over 180 days.

Further research by Lorig et al. (2001) involved a study of the CDSMP over a 2 year period, as a follow-up to the

trial outlined above. Eligible participants (n = 831) were previous participants in the RCT described in the 1999 paper. Participants completed self-administered questionnaires at baseline, 6 months, 1 year and 2 years. They reported significant reductions in 'health distress' together with increases in perceived self-efficacy (p < 0.05), and made fewer visits to physicians and emergency rooms at both 1 year and 2 years from baseline. But despite the positive changes found earlier, an increase in disability was observed at 1 year.

At the end of the second year, self-rated health and energy/fatigue were marginally improved. There were no significant changes in other variables. Confusingly, given the reported initial increase in disability, the paper also reports that there was no significant deterioration between 1 and 2 years. Lorig et al. (2001) highlighted the fact that despite an apparent worsening in physical disability at 1 year, participants maintained or improved other aspects of health status and reduced their use of outpatient healthcare services. Nevertheless, the findings at 2 years may in overall terms be taken to paint a relatively disappointing picture, given the significant improvements in a number of outcome variables identified at 6 months. They suggest that the long-term benefit of participation in the CDSMP may be limited.

## **Generic lay-led self-management programmes in China and Australia**

The CDSMP has been used in 20 countries around the world. However, the search for this rapid review found a limited volume of good quality research published in English on the use of this generic chronic disease management programme.

Fu et al. (2003) conducted an RCT to evaluate the use of the CDSMP in Shanghai. People (n = 954) aged 20 years and over with a medically confirmed diagnosis of hypertension, heart disease, chronic lung disease, arthritis, stroke or diabetes were eligible for participation. All completed a baseline questionnaire and were either assigned to the treatment group (n = 526, CDSMP immediately) or a control group (n = 428, with access to the CDSMP at a later date).

Although the basic CDSMP was used, modifications were made to make its content suitable for Chinese culture. Some sections were deleted, amended or replaced. For

example, many Chinese patients are believed not to be comfortable with discussing death, so this section of the course was deleted. Exercises for flexibility and strength were replaced with familiar Chinese exercises such as taiji (shadow boxing). The course was run for 2-2.5 hour sessions over 6 weeks. One or both group leaders were 'non-health professionals' with a chronic disease themselves.

Questionnaires were completed at baseline and after 6 months. At 6 months, compared with the control group, participants in the treatment group had statistically significant improvements in 13 of 20 outcome variables (for all  $p < 0.05$ ). These included improvements in weekly minutes of exercise ( $p = 0.01$ ), self-efficacy to manage own symptoms ( $p = 0.001$ ), self-efficacy to manage their own disease ( $p = 0.001$ ) and fewer hospitalisations ( $p = 0.04$ ). Mann Whitney U-tests were used to compare outcomes from the intervention group led by lay leaders ( $n = 373$ ) compared with those led by healthcare professionals ( $n = 57$ ). For all but two variables (self-rated health and fatigue) there were no significant differences between the two groups.

Patients in the lay-led groups appeared to enjoy significantly greater reductions in fatigue than those in the professional taught group ( $p = 0.04$ ). But those in the professionally led group had better self-rated health scores than the lay groups ( $p = 0.03$ ). In this respect, the work of Fu et al. (2003) confirms the earlier work of Lorig et al. (1986) with the finding that there is little or no evidence indicating outcome differences between lay-led and professionally led self-management interventions. This counters beliefs that the use of a lay leader is essential for the success of programmes such as the CDSMP.

Australia is another country where there has been significant government support for lay-led and other self-management programmes, and where a significant body of evidence relating to their use in both mental and physical health contexts has been generated (Battersby M, personal communication, 2003). Key developments have included the development of an Enhanced Primary Care package (EPC) designed to promote self-management in primary care settings and a linked Sharing Health Care Initiative (SHCI). In 2004 Australian ministers agreed the creation of a national chronic disease management strategy, embodying self-management programmes as a significant element.

The EPC and SHCI encompass a range of self-management models, including both the specific and generic instruments pioneered by Lorig and her colleagues in the USA.

On the basis of the literature available for this review, there are two key messages to be taken from the Australian experience:

- **the role of professionals such as primary care doctors in facilitating self-management is potentially important.** The Australian approach may have enabled a more cooperative and mutually enabling interface between health professionals, service users and other relevant consumer and support groups
- **self-management support programmes can contribute to meeting the needs of non-European groups.** There is some evidence from research among indigenous Australians that the concepts of self-management may have a relevance which extends beyond mainstream North American and Western European value systems and cultural environments (Battersby 2004).

## Generic self-management programmes within the UK

Within the UK, the Expert Patients Programme (EPP – which might be described as an anglicised version of the CDSMP) is still at a relatively early stage of development. However, it is in a position to go forward on a relatively robust base created during the 1990s by voluntary sector organisations such as Arthritis Care and the Long-term Medical Conditions Alliance (Cooper 2001, 2004).

To date the published evidence base relating to the EPP has been limited, although the results of an RCT (target  $n = 700$ ) and in-depth qualitative investigation are expected to be made available during 2005/6 (National Primary Care Research and Development Centre, University of Manchester). So far the EPP's perceived value is largely based on the positive outcomes of the CDSMP said to have been demonstrated via research conducted in other countries. However, it is important to note differences between the two programmes. While in the USA the CDSMP has recruited participants with a specific set of chronic conditions, and with a diagnosis confirmed by a physician, the EPP is being made available to individuals who identify themselves as having any

chronic condition. In principle, all those who wish to sign up for a course may do so (see EPP website: [www.expertpatients.nhs.uk](http://www.expertpatients.nhs.uk)).

An exploratory British study by Wright et al. (2003) examined the impact of the CDSMP on participants with a range of chronic conditions not assessed in previous studies. Recruitment of participants was through organisations that were members of the Long-term Medical Conditions Alliance (LMCA), which is an umbrella body for national voluntary organisations in the UK. Participants (n = 185) had one of 13 primary chronic conditions (including myalgic encephalomyelitis, polio related disability, endometriosis, depression and haemophilia, as well as more prevalent complaints such as arthritis), and 75% also had comorbidities. The CDSMP was delivered to participants in a manner consistent with that previously described in the literature. Self-administered questionnaires were completed at baseline and 4 months.

Results indicated small to moderate increases in self-efficacy in relation to disease and symptoms, cognitive symptom management and communication with physicians. Small to moderate decreases in anxiety, depressed mood and health distress were also reported. However, no significant changes were found in relation to pain, intrusiveness of condition (measured with five sub-scales), exercise, visits to GPs, visits to specialists, visits to accident and emergency or hospitalisation.

These findings, which show no, or at best moderate changes in outcomes, are disappointing in comparison with the findings of Lorig et al. (1999) in the USA. Wright et al.'s (2003) results may suggest differences between using the CDSMP in the UK and the USA, although they might also be attributable to the less common conditions of many participants in the study. Hopefully, the results of the RCT of the EPP currently underway (National Primary Care Research and Development Centre, University of Manchester) will give a clearer picture of such issues.

Initial reports from an internal evaluation by the Department of Health – presumably based on a self-selected sample of participants – indicate reductions in GP consultations (7%), outpatient visits (10%), accident and emergency attendance (16%) and physiotherapy (9%) (Cayton, 2005). There is also a reported increase in pharmacy visits (18%), health information uptake (34%) and 'better consultations' (33%). This is encouraging,

although the lack of published data on sample selection and size and the research methodology employed, necessitates a cautious approach to interpreting these findings.

The national application of a programme differing in some respects from the original CDSMP might encounter some challenges at variance with those experienced in the USA, albeit that the evidence presented above implies that the basic efficacy of the intervention is likely to remain much the same. Kennedy and Rogers (2003) and Kennedy et al. (2004), in initial work based on the piloting of the EPP, have identified barriers to the implementation of the EPP in England very similar to those identified in the USA by Sobel et al. (2002). Telephone interviews were conducted with primary care trust (PCT) EPP leads (n = 46) and EPP trainers (n = 19) (Kennedy and Rogers, 2003). It was reported that 75% of courses had experienced recruitment difficulties. The EPP initiative appeared more likely to be successful, at least in establishment terms, in:

- urban PCTs
- PCTs with a clearly delegated lead administrator

and when:

- there was networking with other PCTs
- local awareness days and the local press were used to recruit participants.

Local GPs who were enthusiastic about the programme and the availability of local voluntary tutors also increased the likelihood of success. Problems were identified with the term 'expert patients', anxiety about those with severe mental health problems who may attend the EPP, and difficulties recruiting participants. Difficulties were also identified with engaging with healthcare professionals, particularly GPs, who do not rate self-management promotion as a priority. There were also difficulties reported in working with newly formed PCTs, which were likely to have very pressured agendas. For the most recent report on these issues see EPP evaluation team (2005).

These experiences in the pilot phase of the project could indicate that larger-scale problems will have to be overcome as the programme is rolled out across the country. Failure to recruit enough participants might prove to be a fundamental concern in the future of NHS lay-led self-management interventions.

Studies examined in this rapid review have also documented the extent to which participants fail to complete the CDSMP. Drop-out rates have been reported as 30% (Lorig et al. 2004) and 28% (Lorig et al. 1999) of those who initially agree to participate.

The possible impact of such trends, not least on NHS resources, will require monitoring. Such data could also reflect the important reality that many factors influence the day-to-day management of chronic illness by those directly affected and their family and other supporters. 'External' help and support – from whatever official or voluntary source – may not always be experienced as appropriate or helpful.

## Practical problems associated with the CDSMP

Some recent research in the USA on the CDSMP approach has focused on the practical issues associated with setting up and running such programmes, as distinct from their underlying effectiveness. Sobel et al. (2002) examined the views of lay leaders, trainers and site coordinators on implementing the CDSMP. Interviews and questionnaires were used to collect data, which showed that attempts to use the CDSMP are at times unsuccessful and problematic. The researchers' preliminary analysis identified various factors that affect dissemination, including:

- quality of leadership
- adequacy of programme infrastructure (staff time designated, selection of programme champions, creation of mechanisms to manage turnover of staff)
- individual commitment and passion for the programme
- availability of a critical mass of master trainers and lay leaders
- success of processes used for recruiting participants to the programme.

The major barriers affecting the ongoing viability of the CDSMP, once set up, included inadequately supported infrastructures and – not surprisingly – an inadequate number of new participants. This research found that relying on physician referrals as the primary source of recruitment to the CDSMP was not successful, and other ways of assuring recruitment (such as direct mail to potential participants) were needed. Sobel et al. (2002) also noted that recruitment was hampered by the generic

focus of the programme and competition from other disease-specific programmes that appeared more popular with many potential CDSMP users.

## Wider issues relevant to the provision of condition-specific and generic lay-led self-management programmes

It is evident that research literature on both disease specific and generic lay-led self-management programmes is dominated by the work of Kate Lorig and her colleagues. Most of the studies identified during the process of this review used the same intervention (either the ASMP or the CDSMP), albeit in some instances in modified formats, and broadly speaking examined similar outcome measures (see Appendix). It is therefore not surprising that a number of common criticisms and questions requiring further enquiry and elucidation have emerged.

Participants in self-management programmes are inevitably self-recruited to a greater or lesser extent. This self-selecting process may lead particular groups to be more likely to participate in lay-led self-management programmes. For example, Tattersall (2002) highlights the fact that in various studies by Lorig, between 79% and 92% of participants were women. Lorig noted that men and non-English speakers were less likely to attend ASMP groups (Lorig et al. 1999). A study of the CDSMP (Lorig et al. 1999) revealed participants had a relatively high mean level of education. Twenty seven per cent had 12 years of education or less, while 29% had 16 years or more. For a recent study of Bangladeshi participants in a lay-led self-management programme see Griffiths et al. (2005)

Fu et al. (2003), in their evaluation of the CDSMP in China, found that education level significantly influenced reported changes in self-rated health, fatigue and self-efficacy to manage disease in general. Patients with higher education levels had better improvements at 6 months. This implies that if there is an over-representation in programmes by members of more advantaged social groups, trial results could implicitly overstate their likely population impact. It appears on the basis of the information currently available that 'underprivileged' groups are least likely to benefit from access to lay-led self-management programmes. Hence the overall public health 'burden' of chronic illness may not be as

significantly influenced by such programmes as policy makers might hope. Health inequalities may actually be increased by a skewed uptake of programme places.

This leaves researchers with various dilemmas regarding withholding participation in the intervention to try to establish representative samples. As Barlow et al. (2000) highlight, an ethical concern would arise if potential participants were to be denied access to an intervention for which they have put themselves forward. This in part explains why comparisons between 'intervention' and 'control' groups appear to have been possible only for short time periods (typically 6 months).

Follow-ups over longer time periods have, when attempted, therefore been 'uncontrolled'. Barlow et al. (2002) noted that such time frames are inadequate, given the duration of most chronic conditions and the importance of measuring intervention effect durations (see also Newman et al. 2004).

The review by Weingarten et al. (2002) quoted earlier in this review showed that improved chronic illness outcomes can be derived from a wide variety of interventions. Other studies reported here have demonstrated little or no substantive differences in outcomes between lay-led self-management interventions and those with professional leaders (Lorig et al. 1986), or lay-led interventions compared with other interventions (Lorig et al. 2004). Such findings question the particular value of lay-led interventions such as the CDSMP and the EPP when compared with other possible routes towards raising the overall efficiency and effectiveness of health and social care. The findings also raise questions about promoting the development of 'fully engaged' individual and community approaches to coping with health threats and problems. They imply that it would be foolhardy to ignore the possibility that alternative approaches, perhaps focused on modifying 'traditional' professional practices, could provide greater returns.

# Conclusions

In recent decades awareness of the need to address chronic illnesses, and employ self-management and other approaches to minimise the distress and other costs they impose, has risen up the healthcare agendas of all 'rich world' nations. The processes of demographic and epidemiological transition have been the main drivers of such change, along with the emergence of new attitudes towards healthcare delivery in increasingly educated and affluent communities. In countries such as Britain and the USA concern about the rising absolute level of expenditure on health, and the need to confine the use of scarce inpatient and other sophisticated resources to their most effective ends, has also been a significant factor.

In addition, fashions in political thought and the influence of individual service innovators and advocates may (as is more often apparent in the commercial world of pharmaceutical marketing) on occasion have played a significant role. Nevertheless, provision of new low-cost forms of practical support for people living with long-term illnesses has much to recommend it. Promoting self-management and helping individuals to manage potentially disabling conditions better may well have the potential to help some people. Few, if any, responsible commentators would begrudge making interventions such as Stanford University's CDSMP or the EPP approach developed by the Department of Health in England more accessible to health service users likely to benefit from them. Initiatives aimed at further improving the appropriate provision of such services deserve informed support.

But this does not mean that weaknesses in the evidence base on which beliefs about the value of such interventions are based should be ignored. Neither should the fact that even well-intended innovations can sometimes cause harm be overlooked. Given that

promoting lay-led chronic illness self-management programmes appears to be an integral part of a wider move towards healthcare 'modernisation' and the development of a 'patient-led' NHS, it is reasonable to warn that there is a future risk of such hazards materialising.

There is a political dimension to the development and implementation of policies such as the EPP (and other public health initiatives), which ought arguably to be counterbalanced by rigorous research strategies aimed at ensuring their social relevance and capacity to deliver 'value for money'. If decisions about the provision of biomedical interventions are made in large part on the basis of the cost per quality adjusted life year (QALY) generated by alternative investments, there is little or no reason why such thinking should not also be rigorously applied to other forms of individual and community support.

The literature on the sociology of chronic illness and the development and evaluation of lay-led self-management schemes reviewed during the preparation of this report suggests a number of possible problems associated with the presentation and implementation of initiatives such as the EPP. Relevant concerns are as follows.

First, there is the possibility that advocates of public service improvements for people with chronic illnesses have on occasion been tempted to overstate, or use ascientifically, evidence on the relative and absolute effectiveness of interventions such as the ASMP and the CDSMP. Statistics about the burden of long-term conditions may also have been quoted in ways which might distort public understanding of health and healthcare issues. This could lead to wastage of resources, and draw attention away from other valuable ways of helping people to live with long-term conditions.

It may prove important, for instance, to ensure that voluntary sector and informal patient-controlled initiatives for coping with illness and physical and/or mental disability are not undermined by state-run interventions. Similarly, legitimate needs to maintain access to 'conventional' approaches sometimes preferred by patients (such as 'traditional GP care') should not be inappropriately obscured by the creation of new service alternatives.

Second, sociological studies of chronic illnesses have documented a wide range of contextually mediated responses to their occurrence, and a multitude of social variables which influence the experience of such conditions. These factors need to be thoroughly assessed in all attempts to fashion health policy and determine community and other service responses. Although consistent patterns may be discerned in individuals' and communities' successful approaches to living with long-term illness, awareness of the varied social processes underpinning everyday life warn against deriving from such patterns simplistic normative statements about what patients *should* do. Tendencies in this direction might help to explain the difficulties in recruitment and the high drop-out rates already experienced in some programmes.

Third, although lay-led self-management programmes have the potential to enhance participants' abilities to cope with illness, the best evidence to date is indicative of short rather than long-term benefits. Problems such as the documented difficulties experienced in recruitment, retention and the running of programmes, suggest caution in relation to the widespread provision of generic self-management courses. Further, demonstrating *efficacy* among those who volunteer for and successfully complete courses is not the same as showing *effectiveness* in terms of the community level, population wide, management of chronic illnesses.

In conclusion, the evidence and analysis offered here underlines the need for a pluralistic response to the challenge of chronic illness. The requirements of particular communities should be carefully assessed to fashion appropriate local responses. Factors to be taken into account include the sociological (as well as the economic and epidemiological) characteristics of given communities, the nature of the existing resources available to chronically ill people in the community, and the acceptability of professional as well as user-based interventions for supporting self-management. Lay-led

self-management programmes represent one potentially useful approach. But they should be provided as part of a range of formal and informal resources to be chosen by people and families belonging to differing groups and living in differing social circumstances.

## Appendix: Key articles identified on lay-led self-management of chronic conditions

Author, year (country)	Type of intervention	Condition	Total sample (no. in each group)	Age (years)	Groups (if more than one)	Recruitment	Follow-up timeframe	Duration of study	Extent of lay leaders	Method	Outcomes assessed
Barlow and Barefoot, 1996 (UK)	SMC-AS	Ankylosing spondylitis (arthritis)	52 (1: 24 2: 28)	1: 42 2: 42.6 (mean)	1: SMC-AS 2: Control	Invited to attend	1 week prior SMC-AS, 3 weeks, 6 months	6 months	Not documented	Self-administered questionnaires	Arthritis self-efficacy, disease severity, physical wellbeing, psychological wellbeing and exercise
Barlow et al. 1998 (UK)	ASMP	Arthritis	112	59.6 (mean)	n/a	Arthritis Care	Baseline, 4 months, 1 year	1 year	Two lay leaders	Self-administered questionnaires	Arthritis self-efficacy, pain, fatigue, behavioural and cognitive techniques for managing arthritis, exercise, cognitive symptom management, communication with physician, physical functioning and psychological wellbeing
Barlow and Williams 1999 (UK)	ASMP and PIC	Arthritis	12	63 (median)	n/a	Those who had been on the ASMP	Baseline, after the PIC, 4 months after the PIC	4 months	ASMP: Two lay leaders PIC: experts in field disability	Interviews	Participants' views of the PIC
Barlow et al. 2000 (UK)	ASMP	Arthritis	544 (1: 311 2: 233)	1: 57.3 2: 59.1 (mean)	1: ASMP 2: Control	Arthritis Care	Baseline, 4 months, 12 months	1 year	Two lay leaders	Self-administered questionnaires	Arthritis self-efficacy, cognitive symptom management, health, communication with physician, diet, fatigue, pain, anxiety and depression Subsample only – EuroQol
Cohen et al. 1986 (USA)	Modified ASMP	Arthritis	86 (1: 28 2: 24 3: 34)	65.5 (mean)	1: Modified ASMP lay leader 2: Modified ASMP healthcare professional 3: Control	Adverts	First session, last session, 6-8 weeks after ASMP (control only 12 weeks)	6-8 weeks	1: Lay-led (one with condition) 2: Two healthcare professionals	Self-administered questionnaires	Arthritis self-management knowledge, arthritis self-management behaviour, pain, disability, perceived instrumental support, perceived affective support and depression

ASMP = Arthritis Self-Management Program; CDSMP = Chronic Disease Self-Management Program; PIC = Personal Independence Course; SMART = Self-Management Arthritis Relief Therapy; SMC-AS = Self-Management Course-Ankylosing Spondylitis

**Appendix: Key articles identified on lay-led self-management of chronic conditions (cont.)**

Author, year (country)	Type of intervention	Condition	Total sample (no. in each group)	Age (years)	Groups (if more than one)	Recruitment	Follow-up timeframe	Duration of study	Extent of lay leaders	Method	Outcomes assessed
Fu et al. 2003 (China)	CDSMP	Hypertension, heart disease, chronic lung disease, arthritis, stroke or diabetes	954 (1: 526 2: 428)	1: 64.21 2: 63.80 (mean)	1: CDSMP 2: Control	Mass media and personal contacts	Baseline, 6 months	6 months	Two lay leaders (one or both with chronic condition)	Self-administered questionnaires	Exercise, cognitive symptom management, communication with physician, self-efficacy, self-rated health, energy, health distress, fatigue, shortness of breath, pain, disability, illness intrusiveness, depression, social/role activity limitation and usage of healthcare
Haas et al. 2005 (USA)	CDSMP	Back pain	109 (1: 60 2: 49)	77.2 (mean)	1: CDSMP 2: Control	Adverts newspapers, newsletters, community centres, businesses	Baseline, 6 months	6 months	Two lay leaders, both with condition	Self-administered questionnaires	Low back pain, functional disability, perceived self-efficacy, fatigue, emotional wellbeing, self-rated health, depression and self-care attitudes
Lorig et al. 1985 (USA)	ASMP	Arthritis	190 (1: 129 2: 61)	67.4 (mean)	1: ASMP 2: Control	Adverts	Baseline, 4 months, 8 months, 20 months	20 months	Two lay leaders	Self-administered questionnaires	Knowledge, exercise, relaxation, pain, disability and number of visits to physician
Lorig et al. 1986 (USA)	ASMP	Arthritis	100 (1: 34 2: 34 3: 32)	1: 62.1 2: 69.8 3: 61.6 (mean)	1: ASMP by two healthcare professionals 2: ASMP by two lay tutors 3: Control	Adverts	Baseline, 4 months	4 months	1: Two healthcare professionals 2: Two lay tutors (50% with condition)	Self-administered questionnaires	Knowledge, relaxation, exercise, pain, disability and number of visits to physician
Lorig et al. 1989 (USA)	ASMP	Arthritis	707	64 (mean)	n/a	Adverts	Before ASMP, 4 months	4 months	2 lay leaders	Self-administered questionnaires	Knowledge of arthritis, exercise, relaxation, self-management activities, pain, disability and depression
Lorig et al. 1993 (USA)	ASMP	Arthritis	968 (1: 224 2: 177 3: 523 4: 44)	1: 64.2 2: 64.5 3: 55.0 4: 68.3 (mean)	1: ASMP 4 years previously 2: ASMP 4 years previously 3: Course run by healthcare profs 4: Course run by healthcare profs	Adverts	Baseline, 4 months, 4 years	4 years	1, 2: Two lay leaders 3, 4: Healthcare professionals	Self-administered questionnaires	Pain, disability, depression, visits to physicians, self-efficacy for pain and self-efficacy for other symptoms

ASMP = Arthritis Self-Management Program; CDSMP = Chronic Disease Self-Management Program; PIC = Personal Independence Course; SMART = Self-Management Arthritis Relief Therapy; SMC-AS = Self-Management Course-Ankylosing Spondylitis

**Appendix: Key articles identified on lay-led self-management of chronic conditions (cont.)**

Author, year (country)	Type of intervention	Condition	Total sample (no. in each group)	Age (years)	Groups (if more than one)	Recruitment	Follow-up timeframe	Duration of study	Extent of lay leaders	Method	Outcomes assessed
Lorig et al. 1999 (USA)	CDSMP	Heart disease, lung disease, stroke or arthritis	1140 (1-664 2-476)	1: 65.5 2: 65.5 (median)	1: CDSMP 2: Control	Adverts	Baseline, 6 months	6 months	1: Two lay leaders (71% with chronic condition) 2: None	Self-administered questionnaires	Exercise, cognitive symptoms, communication with physician, self-rated health, disability, social/role activity limitation, pain, psychological wellbeing, fatigue, health distress, shortness of breath and usage of healthcare
Lorig et al. 2001 (USA)	CDSMP	Heart disease, lung disease, stroke or arthritis	831	At year 1: 65.3 At year 2: 64.8	n/a	CDSMP participants from Lorig et al. (1999)	1 year, 2 years	2 years	n/a	Self-administered questionnaires	Self-rated health, disability, social/role activity limitation, fatigue, health distress, self-efficacy and usage of healthcare
Lorig and Battersby 2003 (USA)	CDSMP	Back pain	422	44	1: CDSMP 2: Control	Not documented	1 year	1 year	Two lay leaders	Self-administered questionnaires	Disability, health distress, role function, self-efficacy and usage of healthcare
Lorig et al. 2004 (USA) Study 1	SMART and usual care	Arthritis	1090 (1: 522 2: 568)	62.2 (mean)	1: SMART 2: Usual care	Arthritis, rheumatism and ageing databank	Baseline, 1, 2 and 3 years	3 years	None	Self-administered questionnaires	Disability, pain, depression, role function, global severity, physician visits, rheumatology visits and self-efficacy
Lorig et al. 2004 (USA) Study 2	SMART and ASMP	Arthritis	341 (1: 180 2: 161)	65.2 (mean)	1: SMART 2: ASMP	Arthritis, rheumatism and ageing databank	Baseline, 1, 2 and 3 years	3 years	1: None 2: Two lay leaders	Self-administered questionnaires	Disability, pain, depression, role function, global severity, physician visits, rheumatology visits and self-efficacy
Wright et al. 2003 (UK)	CDSMP	Various (n = 13)	185	53 (mean)	n/a	Long-term Medical Conditions Alliance members – specific condition organisations	Baseline, 4 months	4 months	Two lay tutors, both with chronic condition	Self-administered questionnaires	Self-efficacy, symptom management, communication with physician, fatigue, pain, shortness of breath, anxiety, depression, health distress and intrusiveness of condition

ASMP = Arthritis Self-Management Program; CDSMP = Chronic Disease Self-Management Program; PIC = Personal Independence Course; SMART = Self-Management Arthritis Relief Therapy; SMC-AS = Self-Management Course-Ankylosing Spondylitis

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