

## Chronic illness, expert patients and care transition

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**Abstract** During the last century demographic and epidemiological transitions have had a radical impact upon health and health service provision. A considerable body of research on the sociological aspects of living with chronic illness has accumulated. Debate has focused on how social environments shape disability-related experiences, and the extent to which individual responses define health outcomes. Through the establishment of the Expert Patients Programme (EPP) in 2001, the Department of Health has sought to enhance NHS patients' self-management capacities. This paper discusses three areas relevant to this: the policy formation process leading up to the EPP's present stage of development; the evidence base supporting claims made for its effectiveness; and the significance of psychological concepts such as self-efficacy in approaches to improving public health. The conclusion discusses NHS developments in primary care and public involvement in health and healthcare, and the implications that initiatives such as the EPP carry for the future. It is argued that to facilitate a constructive process of 'care transition' in response to epidemiological and allied change, awareness of cognitive/psychological factors involved in illness behaviours should not draw attention away from the social determinants and contexts of health.

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### Introduction

Over the course of the last century the processes and consequences of demographic and epidemiological transition have had a radical impact upon health and health service provision in 'developed' countries such as the UK. The ageing of populations, driven by falling infant and child death rates, smaller family sizes and longer average adult life expectancies, has – along with the social and economic forces associated with industrialisation, urbanisation, female emancipation and shifts from manual to 'knowledge-based' occupations – been linked with profound changes in healthcare needs, demands and delivery capacities (Taylor and Bloor 1994, Gray 2001).

All aspects of health and illness experience (from the psychodynamics of family relationships to the degree to which people with physical or mental disabilities are accepted without stigma) have been influenced by such trends. Since the end of the Second World War, greater prosperity coupled with the availability of more effective pharmaceutical and other medical technologies (Bunker 2001) have also helped to create new public health

challenges and opportunities. Increasing proportions of the population are surviving to live for substantial times with chronic illnesses and long-term complaints such as arthritis, diabetes and potentially disabling degrees of atherosclerosis. More people are also living for prolonged periods with conditions such as cancer or HIV infection.

A considerable body of research and evidence on the sociological and allied aspects of living with chronic illness has now accumulated. Debates on the origins and social patterning of chronic illness in the late 1950s and 1960s were supplemented by community-based surveys of the need for medical and social care (Bury 1997). These documented, *inter alia*, the nature of social support and the impact of illness on family and working life (Patrick and Peach 1989, Anderson and Bury 1988). It was, however, the work of Strauss and his colleagues which was most instrumental in putting the everyday effects of chronic illness on the sociological map. In his early work Strauss emphasised the public health impact of chronic conditions, and later spelled out what he took to be its implications for the development of health services (Strauss 1975, Corbin and Strauss 1988).

In the UK, as well as in the US, a series of studies have traced the links between illness, disability, the self and society. The meanings and significance of illnesses to the individuals and groups whose identities are affected by them have been extensively documented, as has the management of the body (the individual's physical being) in social interaction. Issues relating to the disguising or disclosing of symptoms, stigma, social exclusion and the impact of illness on relationships and life chances have been discussed, along with the importance of illness narratives to people living with chronic conditions (Charmaz 2000, Bury 2001, Frank 1995, Kelly and Field 1996, Kelly and Millward 2004). A vigorous exchange also ensued between disability activists and medical sociologists about the social and political dimensions of disabling illness. As Barnes and Mercer (2003) show, however, some of the lines drawn in this debate have now begun to fade. The main point of contention between its participants concerned the degree to which chronic medical symptoms and bodily impairments should be regarded as directly causal in the experience of disability. For some activists, 'society' as a collective entity was (and is) essentially responsible for the difficulties that individuals with mental or physical impairments may encounter: medical sociology's exploration of corporeal experience was, from their perspective, anathema.

On the other hand, medical sociologists argued that their work in this area contributed usefully to understanding the situations and adaptive responses of people and groups to potentially disabling long-term conditions – Corbin and Strauss (1991) referred to such processes of adjustment as 'comeback' – even when medically defined symptoms and models were apparently the primary focus of attention. At times the debate surrounding this area became both intense and bitter. Yet, in retrospect, it is arguable that all sides were concerned to contextualise appropriately the problems related to chronic conditions.

Over the last few years, another issue has come to the forefront of public and political debate on chronic illness and the place of human agency (that is, purposive individual or collective action), as distinct from social structures and norms, in determining outcomes. Through the establishment from 2001 of the Expert Patients Programme (EPP), the Department of Health (DoH) has in England – via a small, but in policy terms important, centrally funded National Health Service (NHS) programme – sought to enhance patients' self-management capacities.

Whilst sociologists have taken self-care or management to be central to responses to chronic illness, enhancing supportive interventions has not normally been their prime concern. Advocates of innovative approaches such as the EPP may argue that, in the past, 'public health' as a discipline within the NHS has also lacked a sufficiently focused emphasis on directly improving services and outcomes.

The EPP is designed to introduce an English version of a lay-led chronic disease self-management programme originally pioneered by a US researcher, Professor Kate Lorig (who drew on the work of Strauss in fashioning her views – Lorig 2002) and her colleagues in Stanford University (DoH 2001, Lorig *et al.* 1985, Lorig *et al.* 1999, Lorig *et al.* 2001). Such courses involve a brief – typically six-week – series of two-to-three-hour weekly meetings led by ‘lay’ tutors, who themselves have chronic conditions.

A manual introduces a series of topics appertaining to the development of self-management competencies. Important elements in this approach include goal setting – and with this the creation of opportunities for individuals successfully to master illness-linked challenges – together with the provision of positive role models, peer support and information on techniques for overcoming anxiety and uncertainty. The EPP’s advocates believe that such courses will in time have a major impact on reducing healthcare costs and improving health outcomes.

Against this background of high-level-led NHS innovation and the developing sociology of chronic illness outlined above, this paper discusses three main areas relevant to the introduction and future of the Expert Patients Programme: first, the policy formation process leading up to the present stage of EPP development; second, the evidence base supporting claims made for the EPP’s effectiveness; and, third, the significance of psychological concepts such as self-efficacy in this and other approaches to improving public health, and the relationships between the psychological and sociological models and theories in the context of health improvement. In addition, a concluding section discusses the possible costs and benefits linked to the EPP initiative. It notes current NHS developments in fields such as primary care reform and patient and public involvement in health and healthcare, and explores the implications that initiatives such as the EPP may carry, as part of a ‘care transition’, for the future identities and working practices of health professionals such as general medical practitioners, nurses and community pharmacists.

### **Policy formation and the origins of the EPP**

Following the election of a Labour Government in 1997, ministers sought to ‘hit the ground running’ in health and social care with a raft of restructuring initiatives. The then Secretary of State for Health, Frank Dobson, and his advisers (some of whom had been influenced by opportunities to study in the United States, as well as by experience in the British public service environment) were ready with new policies to be put in place via – in England – the Department of Health. In December 1997 the White Paper *The New NHS: Modern, Dependable* (Cmnd 3807) set out a programme leading to the creation of Primary Care Trusts (PCTs), Strategic Health Authorities, the National Institute for Clinical Excellence and the Commission for Health Improvement (now the Healthcare Commission).

These and other proposals for modernisation and quality improvement were welcomed by many supporters of the NHS, who saw them as a prelude to better-funded direct public health service provision. Within the field of public health itself there was also a strong feeling that the change of government would be beneficial for those seeking to ensure that health policies should be based on an evidence-based awareness of the wider social determinants of health and illness patterning and experience. (See, for instance, Whitehead *et al.* 2000, Graham 2000.) The rapid establishment and publication of the Acheson *Independent Inquiry into Inequalities in Health*, some 20 years after the ‘Black’ report on this topic, was in this context widely taken to be evidence of a marked change in national direction (Acheson 1998).

Similar expectations surrounded the publication in 1999 of the White Paper *Saving Lives: Our Healthier Nation* (Cmnd 4386). This set out the ‘new Labour’ government’s plans for public health improvement. It was also taken by many observers to represent a resolve to go beyond a reiteration of the ‘adopt a healthier personal lifestyle’ approach to promoting positive health. The new approach would focus more on the community and broader social factors influencing the abilities of individuals to change their situations and behaviours.

*Saving Lives: Our Healthier Nation* emphasised the challenge of managing chronic disorders, an area relatively neglected in many previous health policy documents. It commented 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’. Citing arthritis and allied care programmes (developed not only in the US, but also in the UK by voluntary sector organisations such as Arthritis Care and the Long-term Medical Conditions Alliance – Cooper 2001, 2004, Jones 2005), the White Paper argued that ‘trained staff and volunteers’ with arthritis were able to help people take more control of their lives, and make best use of professional advice. It announced that the Chief Medical Officer (CMO), Professor – now Sir – Liam Donaldson, was 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 a confirmation that promoting the self-management of chronic disorders was becoming a central element in the Department of Health’s thinking about healthcare improvement. *The NHS Plan* set out a vision in which the ‘NHS will become a resource which people routinely use to help look after themselves’, and linked it in with other developments such as *NHS Direct* (Cmnd 4818–1). Not long after this the findings of the Expert Patients Task Force were published, and the establishment of the Expert Patients Programme began (DoH 2001).

As previously noted, the CMO’s initiative was in large part based on the work of Kate Lorig and the members of the Stanford University-based team that had pioneered the Arthritis Self Management (ASMP) and Chronic Disease Self Management programmes (CDSMP) in California. Referring to Lorig’s work, Donaldson subsequently stated that ‘nearly 10 million people’ in England live with a chronic disease, and that in the past the ‘wisdom and experience’ of the patient had not been fully acknowledged by the medical community (Donaldson 2003). He explained that the EPP was intended to correct this failing, and that it was to be ‘a centre piece of the NHS approach to chronic disease management in the 21<sup>st</sup> century’. He concluded that ‘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’ (2003: 1280).

From 2002, the pilot phase of the EPP and its roll-out across England, which currently remains supported via a centrally allocated budget (Wales is extending its programme from two initial pilot areas), was accompanied by a raft of further policy statements. Despite the limited scale of the initial investment made in the EPP, and the limited attention sometimes paid to it within PCTs (Jafri *et al.* 2003, Kennedy *et al.* 2003, 2004, EPP Evaluation team 2005), government publications continued to stress its significance in high level strategic thinking on healthcare delivery in the early 21<sup>st</sup> century. For example, *The NHS Improvement Plan* (DoH 2004) devoted a whole chapter to the topic of supporting people with long-term conditions.

This began with the statement that ‘about 60 per cent of adults report some form of long-term chronic health problem’, and proceeded to outline a model for tackling this seemingly gargantuan problem. At the highest level of intervention, this demanded ‘case

management' for those with multiple problems and a high propensity to use both primary and costly secondary care services. The 2004 *Plan* announced that 'over 3,000 community matrons' were to be introduced into the NHS by 2008, in order to deliver enhanced case management to '250,000 patients with complex needs'. Below this *The NHS Improvement Plan* prescribed 'disease management' for those with single serious conditions such as diabetes or heart disease. It noted that the National Service Frameworks define expected standards of care, and that the new contracts for GPs and other practitioners would give incentives for the provision of effective disease-management services.

The *Plan* also indicated that below the top two tiers of case management and disease management the vast majority of individuals living with chronic conditions – 70-80 per cent of all potential service users – would be helped by self-management programmes. It stated that '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'. It envisaged that the EPP would be 'rolled out' by 2008, 'allowing thousands (sic) more patients to take control of their own health and their own lives' (DoH 2004: 36). Box One summarises other recent policy documents that refer to, and have helped further to elucidate, the government's thinking about the EPP and its goals.

It would not be possible to explore in detail here all the questions that a comprehensive analysis of the above documents might generate. For instance, there are concerns about the extent to which the approach embodied in these documents and in *The NHS Improvement Plan* represent an attempt to import into the UK financial and care-management systems employed by healthcare insurers and providers in the United States by organisations such as Kaiser Permanente and the United Health Care Group. The latter organisation originated the Evercare case/disease-management programme. The perceived hazards that such approaches might not be fully consistent with the strengths and values of the NHS, or meet optimally the needs and preferences of the communities it serves, have been widely debated (Ham *et al.* 2003, Hutt *et al.* 2004, Pollock 2004, Roland *et al.* 2005, Wilson *et al.* 2005.)

From the perspective of this paper, however, there are four key issues to highlight at this point. The first relates to the prevalence of chronic illnesses, and the significance of the ways in which relevant data are used in policy statements.

There is epidemiological and other survey evidence (ONS 2002a, 2002b, British Household Survey 2001) that may be cited to justify claims like 'six in ten adults have a chronic illness' or that some '17.5 million adults may be living with a chronic disease' (DoH 2003: 2). However, most national surveys give lower estimates for the adult population as a whole, and the meaningfulness and practical value of such figures is questionable. Their use in public debate might falsely suggest that in modern society 'sickness' is more prevalent than in the past, or in poorer societies, even though this is manifestly not the case (Sen 2002). At worst, it may even be seen as a form of 'disease mongering' by groups with an interest in influencing health-related spending and policies.

From a sociological perspective it could also undermine political and professional awareness of the complexity of illness experiences, and people's abilities to overcome health problems. Many individuals striving to 'live well' with long-term mental or physical conditions resist being labelled or treated as either disabled or chronically ill. Apparent failures by policy makers and others to understand adequately the limits and complexity of chronic illness estimates – and how individuals, families and communities in reality cope with illness – could impair efforts to promote better health and optimally effective patterns of healthcare utilisation (Gooberman-Hill 2003, Lawton *et al.* 2005).

### Box One

The public health White Paper *Choosing Health: Making Healthier Choices Easier* (Cmnd 6374). This in part reinforced the Improvement Plan's proposals for community matrons. It also stressed the importance in modern societies of consumer freedom to select options which maximise their personal welfare, given the realities of their situations.

The second Wanless/Treasury report on public health, *Securing Good Health for the Whole Population* (Wanless 2004). Following Sir Derek's 2002 report *Securing our Future Health* (Wanless 2002), which marked the Treasury's acceptance of the Prime Minister's decision significantly to increase NHS funding, this publication offered the conclusion that future healthcare cost growth could best be moderated by the population becoming 'fully engaged' in health promotion, protection and care. Its analysis pointed to the fact that population wide health can, in many instances, most equitably and cost effectively be preserved by universally applicable regulatory interventions such as 'seat belt laws' and smoking bans. But the report also noted that from a political and wider social perspective gaining – or at least appearing to gain – the voluntary agreement of electors with prescriptions for better public health may be regarded as a critical priority.

The Department of Health papers *Improving Chronic Disease Management* (DoH 2003), *Supporting People with Long Term Conditions: An NHS and Social Care Model* (DoH 2005a) and *Self-Care – A Real Choice* (DoH 2005b). These underlined the fact that the self-management of chronic conditions and the establishment of the EPP can be seen as part of a wider policy framework, running throughout 'modern' strategic thinking on public health improvement and health service development.

Briefly stated, the second key issue relates to the possible tensions between health improvement policies presented as being based on an informed understanding of the broad social determinants of health and illness, and implementation programmes focused more on changing individual behaviours and ways of thinking. The latter may run the risk of 'blaming the victims' rather than addressing the social factors more fundamentally responsible for their illnesses.

The third relates to the purposes underlying the apparent desire of policy makers to 'brand' the EPP and self management promotion more generally as an NHS initiative. This might be seen as cutting across rather than building on existing work in the voluntary sector, and driving a process of 'incorporation' of community initiative and lay experience within politically and/or professionally controlled structures.

The final issue is associated with wider processes of change and reform in primary care, and the management of healthcare. This involves factors ranging from the changing nature of professional/patient relationships to the extent to which more aggressively managed

systems of care may have an impact not only on clinical judgement but also – albeit perhaps unintentionally – on health service users’ freedoms and opportunities to cope with the challenges of chronic illness in the ways they find most effective and appropriate.

Aspects of these topics are discussed further below, following a review of the evidence base relating to lay-led self management programmes and the claims made for the effectiveness and efficiency of the EPP.

### **The EPP/lay-led self-management evidence base**

As previously noted, the EPP has in its pilot phase been a nationally funded, centrally directed programme. Although the sums of money allocated to it may be regarded as small in governmental terms, this is an unusual situation, given the recent emphasis on the importance of devolving resource allocation decisions to PCTs. At its start two national trainers, Jim Philips and Jean Thompson (who in November 2004 won the Guardian’s public services ‘diversity and equality’ award) were appointed to train and employ – through Strategic Health Authorities – as accredited local trainers. These individuals in turn train local ‘expert’ volunteer tutors, who will have experienced chronic disorders themselves and already been on a self-management course.

It is, then, these tutors who provide courses for patients. They comprise six (and sometimes a final recapping seventh) weekly sessions, and may be run with or without the local trainers being present. Each session is typically two or two-and-a-half hours long, and will involve about eight or 10 people. They follow a pre-determined format based on the chronic disease self-management programme developed by Lorig. Set topics include: techniques to deal with frustration, fatigue, pain and isolation; improving exercise for strength, flexibility and endurance; developing appropriate use of medication; communicating effectively with family, friends and health professionals; improving nutrition; and finally, learning how to evaluate new treatments.

Although precisely structured, the approach employed is non-technical, and easily accessible to people with a wide range of educational backgrounds. Participants are given an accompanying course book, and each session involves the tutors (it is recommended that courses should always be led by two trained individuals) presenting the week’s new work and receiving feedback from course members about their experiences and the achievement of previously agreed goals. Course discussions frequently end with comments and additional ideas from those taking part being written up on a flip chart.

There is already much anecdotal evidence about the positive effects of EPP courses. Individuals working in the programme, and patients who have been on it, have provided powerful personal testimonies as to its transforming impact, to the national media, and at national and other meetings. Examples can be accessed via the programme’s website ([www.expertpatients.nhs.uk](http://www.expertpatients.nhs.uk)).

At the same time, preliminary data gathered by the EPP’s centrally employed managers emphasise not only high levels of ‘customer satisfaction’, but also the achievement of apparently dramatic success relevant to the achievement of national performance targets. Initial reports (Cayton 2005) claim reductions in GP consultations (7%), outpatient visits (10%), accident and emergency attendance (16%) and physiotherapy use (9%). At the same time they indicate an increase in community pharmacy visits (18%), health information service use (34%) and ‘better consultations’ (33%) amongst EPP course attendees.

Such anecdotal and managerially assembled evidence should not be ignored. Yet there is an obvious danger that EPP participants with less positive experiences will not be motivated

to communicate them publicly, and that civil servants and NHS managers may wish to avoid being responsible for the transmission of negative messages. Published EPP Strategic Board minutes suggest that tendencies for enthusiasts to overstate its effectiveness should be balanced by careful research, even though the 'level of proof' is reasonably required to support public health innovations, legitimately a matter of debate. (See minutes of the EPP board 25<sup>th</sup> October 2004: [www.expertpatients.nhs.uk/publications.aspx?category=4](http://www.expertpatients.nhs.uk/publications.aspx?category=4)).

Significant questions remain to be explored, not least because research undertaken in both the US and the UK has revealed relatively low levels of take up amongst populations offered self-management courses. The reported levels of subsequent participation by acceptors also seem disappointing in some instances (Sobel *et al.* 2002, Kennedy *et al.* 2003, Griffiths *et al.* 2005). It therefore seems that even if high levels of behavioural change have in some instances been associated with EPP/CDSMP course attendance, the groups involved may have been highly selected.

The substantive findings available on the outcomes of the EPP programme itself (which unlike its US equivalent is open to patients with any chronic condition) are currently scant. A randomised controlled trial being undertaken at the National Primary Care Research and Development Centre in Manchester and the University of York is about to be published. The extent of the research published on both disease specific and more generic chronic disease, lay-led, self-management schemes, is also limited. It is largely made up of papers published by Lorig and her Stanford University colleagues, plus contributions from a small number of other investigators working outside the US. (See, for instance, Barlow *et al.* 1998, Barlow *et al.* 2000, Fu *et al.* 2003, Griffiths *et al.* 2005).

Generally relevant reviews of patient education-oriented initiatives (Weingarten *et al.* 2002), self-management courses for specific disease groups (Newman *et al.* 2004) and case management in chronic illness (Hutt *et al.* 2004) provide a mixed picture. Weingarten's analysis, for example, found improvements in provider adherence to guidelines and patient responses to chronic disease-related problems, stemming from a range of over a hundred different types of intervention employed in the context of a number of conditions. The success of such a plurality of measures in producing positive outcomes suggests that participation may in itself be more important than the precise nature of a particular programme. Lorig's work on different modes of delivery of self-management courses raises similar issues (Lorig *et al.* 1986, 2004). This implies that, without further comparative research, claims that self-management interventions have to be lay led in order to achieve good results must be considered questionable. Present interest in providing an 'online' version of the EPP may serve to underline this point.

The current authors have recently conducted a review of the present state of knowledge regarding lay-led chronic illness self-management programmes (Bury *et al.* 2005). It would not be appropriate to reproduce that evaluation here. But observations and conclusions that it is relevant to summarise here include the following:

1. Although the condition specific Arthritis Self Management and generic Chronic Disease Self Management programmes pioneered by Lorig and her colleagues may be said to have been subject to randomised trial, the methodologies employed in the available studies have significant weaknesses

The point has already been made that evaluations that involve self-selected volunteers, rather than representative samples of potential beneficiaries, inevitably lack external validity. This concern alone casts doubts on most, if not all, of the published studies on lay-led self-management programmes, though this is not to say that individuals who feel that they would like to attend an EPP or similar course could not benefit from doing so.

Looking at individual investigations in further detail, perhaps the single most significant paper published in recent years is that of Lorig *et al.* (1999). The research described involved 952 participants in the CDSMP, suffering from four 'physician-confirmed' diagnoses: heart disease, lung disease, stroke and arthritis. All were aged 40 and over. The courses were lay led, though 38 per cent of the tutors were either students or health professionals. This randomised control trial reported on outcomes amongst participants and controls at six months. The control arm was made up of individuals judged eligible to join the programme, but held on a six-month waiting list. Following the end of this period, these controls were allowed to join the programme. Thus, no longer-term controlled follow up was possible. Regardless of ethical or other practical reasons for this design decision, it limited significantly the value of its findings to those observed at six months.

A range of methods of assessment were used in order to evaluate the programme's effectiveness. The outcomes were grouped into what the authors call 'three primary classifications of outcomes variables' (Lorig *et al.* 1999: 7). These classifications comprised 15 outcome measures, in relation to which statistically significant differences were recorded in 11 areas. (It is of interest that no significant differences were reported in the domains of experienced pain or physical discomfort, shortness of breath or psychological wellbeing.) It may be argued that the trial was essentially exploratory in nature, because no clear primary outcome was identified. A later paper, reporting a two-year uncontrolled follow up of this trial, described relatively few sustained improvements (Lorig *et al.* 2001).

Similarly, in a British trial of the Arthritis Self-Management Programme (Barlow *et al.* 2000), participants wishing to join the ASMP were allocated either to the programme (the intervention arm) or to a four-month waiting list (the control arm). Outcomes were assessed at four and 12 months after the original intervention. Here again, the study design employed precluded the comparison of 'untreated' control and intervention group members at the second of these points.

Barlow and her colleagues found that at four months significant improvements were seen in the intervention group in 'cognitive symptom management', 'communication with physician', health behaviours such as relaxation, and a range of psychological measures. However, unlike the Lorig study, the method of analysis used did not permit a fully satisfactory comparison of the intervention and control groups, because it failed to adjust adequately for differences between the intervention and control groups at the baseline. No analysis of covariance was employed – each arm of the study was analysed separately. The sample was drawn from members of the Arthritis Care Branch Network, which could again be seen as limiting the external validity of the results.

2. The findings of the studies available, regardless of their technical robustness, are not indicative of outcome improvements as significant or sustained as may sometimes be assumed

It is not possible to calculate from the research so far undertaken the extent of benefit that an average population of individuals who contract a chronic illness might gain from SMP courses, or to extrapolate from the published data the duration of the period for which they would be advantaged. Despite claims by supporters of Lorig and her work that course attendance confers permanent benefits, it might be that such interventions serve mainly to accelerate a process of adjustment (or 'comeback') that would in any case occur. Evaluations of drug interventions designed to delay the progression of conditions such as Alzheimer's disease, Parkinsonism and multiple sclerosis seek to differentiate between transient and long-term benefits. It is reasonable to argue that evaluations of the EPP and other public health interventions should be no less rigorous in taking into account 'duration effects'.

Further, the observed level of benefit stemming from self-management programme participation has in many instances been relatively modest, albeit that this is not to deny positive findings when they have been observed. From a financial perspective, for instance, the 1999 CDSMP study reported savings in hospital costs of \$800 at US expenditure levels (circa £500) over a period of six months. These arose from an average reduction per course participant, in hospital inpatient care days used, of about 0.8 of a day during the study period.

Given the pressures on patients and healthcare providers in the United States and, indeed, in the UK, even modest reductions in demand might represent a welcome level of benefit. Yet it is currently uncertain as to whether or not the gains seen in some US studies will be generated in the different UK health and social care environment. It is also not clear how long such a cost advantage might endure. One possibility is that initial savings could be counter-balanced by subsequent rebounds. Recent research was designed to evaluate the impact of an adapted course based on the CDSMP/EPP amongst British Bangladeshi adults with a chronic illness (a vulnerable and relatively high-cost population – Griffiths *et al.* 2005). This did not report reduced hospital stays or costs, although benefits were reported in fields such as depression levels. (See also Wright *et al.* 2003.)

3. The research findings available do not provide strong reason to believe that lay-led self-management programmes are inherently more likely to generate significantly better outcomes than similar professionally-led interventions

In addition to the comment offered previously on this topic, studies by Lorig (Lorig *et al.* 1986) and other researchers (such as Fu *et al.* 2003) themselves offer challenges to suggestions that the use of lay leaders confers significant health-outcome advantages, even though the potential of individuals with long-term conditions to serve as positive role models should be duly recognised. Perhaps the most important point to make is that the competencies that ‘lay’ contributors can offer should not be permitted to draw attention away from the need to change professional attitudes and practices, and the value of constructive, ‘grown up’, professional/patient relationships (Coulter 1999).

Reports from Australia indicate that professionals can work directly to promote self-management skills in a range of populations (Battersby 2004). Although it was argued by Lorig and her fellow researchers that the use of lay tutors would allow significant financial savings, developments in the training and payment of ‘lay’ course contributors may call this into question. The full costs of delivering interventions such as the CDSMP should be considered in any economic appreciation of their net benefit.

4. Alternative forms of support may produce outcome improvements comparable to those achieved via the provision of self-management courses

A recently published article by Lorig *et al.* (2004) compared the use of the ASMP lay-led approach with a non lay-led, mail-delivered tailored self-management intervention (SMART). It reported findings from two trials. The first study compared participants randomised to the SMART with participants receiving the usual care. The second randomised participants either to the SMART or the ASMP. Outcomes were assessed at one, two and four years. The results of this work indicate that both the established arthritis self-management programme and the non-lay-led intervention conferred significant benefits over ‘usual care’ package, albeit that after two years the SMART programme gains appeared to fade.

The key point to record here is that many people may not need to join a group or have face-to-face contact with a tutor in order to acquire enhanced self-management capabilities. Some might prefer an alternative. As already noted, in the UK and elsewhere internet/IT-based versions of the EPP and other self-management support schemes are now being developed.

5. The fundamental mechanism to which Lorig and her colleagues attribute the positive effects of their self-management programmes relate to enhancements in their participants' levels of self-efficacy, rather than learning specific information or techniques

Many health professionals appear to interpret the term 'expert patient' (which in the US is more often used to describe patients who contribute to professional teaching, rather than those who have been on self-management programmes) to mean that health service users taking part in the EPP are being educated about their illnesses, in order to develop an understanding of their condition comparable to that of, say, doctors or pharmacists. But Lorig has stressed that her research indicates that changes in health outcomes stemming from participation in self-management courses should primarily be ascribed to raised levels of self-efficacy – or what might be described as context specific self-confidence – rather than the acquisition of specific formal knowledge or skills.

This is consistent with a large body of research in the health-promotion field, at least in as much as the latter has repeatedly shown that changes in knowledge levels alone do not normally change health-related behaviours. Moreover, as Lindsay Prior (2003) has shown, patients may not be as knowledgeable as those emphasising 'lay expertise' sometimes suppose. The implication is that the EPP's public health benefits stem essentially from cognitive changes, taking place at an individual level. Although these may open the way to new learning about given conditions and interventions, enhanced self-efficacy per se should not be confused with traditional 'health-education' objectives involving the transmission of highly specific information. Such conclusions raise a number of important issues, from both a sociological perspective and the viewpoint of health services development. It is to these that this paper now turns, following a brief further exploration of the term self-efficacy and its relevance to chronic illness self-management and problem solving.

### **Raising self-efficacy – a 'magic bullet' for enhancing self-care and achieving 'full engagement'?**

The origins of 'self-efficacy' as a concept are associated with an area of psychology known as learning theory, and linked to ideas such as 'learned helplessness'. This last suggests that in some circumstances people experience events and interactions that 'teach' them to lose their ability to respond effectively to given challenges. Gaining increased self-efficacy – a concept most notably developed in the work of Albert Bandura of Stanford University – implies an opposite effect. Bandura (1994) has argued that people can change their beliefs about 'their capabilities to produce designated levels of performance', and that because much human motivation is cognitively generated this in turn can lead to significant improvements in behaviour.

He has commented that 'a strong sense of efficacy enhances human accomplishment and personal well-being in many ways. People with high assurance in their capabilities approach difficult tasks as challenges to be mastered rather than as threats to be avoided. Such an

efficacious outlook fosters intrinsic interest and deep engrossment in activities. They set themselves challenging goals and maintain strong commitment to them. They heighten and sustain their efforts in the face of failure. They quickly recover their sense of efficacy after failures or setbacks. They attribute failure to insufficient effort or deficient knowledge . . .’ (Bandura 1994: 71).

‘In contrast’, Bandura adds, ‘people who doubt their capabilities shy away from difficult tasks which they view as personal threats. They have low aspirations and weak commitment to the goals they choose to pursue. When faced with difficult tasks, they dwell on their personal deficiencies, on the obstacles they encounter, and all kinds of adverse outcomes rather than concentrate on how to perform successfully. They slacken their efforts and give up quickly in the face of difficulties. They are slow to recover their sense of efficacy following failure of setbacks . . .’ (1994: 1).

In Bandura’s view, high levels of perseverance contribute to positive performance accomplishments. Good psychological health is also related to such traits: ‘a low sense of efficacy to exercise control produces depression as well as anxiety . . . However, even in adversity, resilient individuals can reach positive outcomes’ (1994: 1). Bandura goes on to provide examples of successful individuals who achieved ‘eminence in their fields’, (1994: 1) despite facing various difficulties. However, from a sociological viewpoint such an approach appears to be both anecdotal and strongly normative. Its cultural reference points may reflect the values and ideals of the ‘American dream’, rather than a more general understanding of human preferences and goals.

Nevertheless, Lorig and her co-workers have underlined the importance of Bandura’s work in their own explanations as to how the ASMP and CDSMP generate benefit. Indeed, Bandura has been a collaborator on some of Lorig’s projects. In a paper delivered to an international conference on chronic disease self-management held in Sydney in 2000, Lorig and Holman (2000) discussed the necessary skills for effective self-management. These (in their view) include competencies in ‘problem solving, decision making, resource utilization, forming a patient/health care provider relationship, and taking action’ (2000: 9).

They went on to say that rather than teaching patients how to solve particular problems, the aim of the self-management approach was to teach problem solving itself. They stated that: ‘traditional health promotion and patient education programs have operated under the assumption that people should change behaviors in order to improve health status . . . While there is little question that changing these behaviors will probably impact future health, this same assumption may not hold for people already living with chronic conditions’ (2000: 14). The suggestion being made is that the latter should start by changing their thinking.

For Lorig and Holman promoting enhanced self-efficacy opens the way to a wide range of productive approaches to managing chronic illness. They argue that ‘self-efficacy beliefs can be enhanced through performance mastery, modelling, reinterpretation of physiological symptoms and social persuasion’, and add that ‘enhanced self-efficacy leads to improved behavior, motivation, thinking patterns, and emotional well being’ (2000: 15). In their Australian presentation they also claimed that the evidence from their empirical studies of the CDSMP shows that ‘both base line self-efficacy and changes in self-efficacy are associated with future health status’ (2000: 15). It is important to note, however, that the original CDSMP trial in fact reported no significant change in domains such as the ‘psychological well-being’ of participants despite increases in self-efficacy (Lorig *et al.* 1999).

The potential capacity of insights relating to raising self-efficacy and enhancing (or unlocking) the problem-solving skills of people facing illness to contribute to the future improvement of all forms of health promotion and care deserves serious examination. Yet

there are a variety of reasons to exercise caution in this context. One of these relates to the problems involved in identifying causality in the complex fields of human thought and behaviour. As with other research on psychological processes relevant to health (including that on topics such as the impact of high or low self-esteem, varying health beliefs, and an internally, as opposed to an externally, focused 'locus of control'), significant questions may arise. These are not only about the extent to which given cognitive factors explain observed behavioural variances, but also the causal direction of postulated relationships.

Self-efficacy has been posited as a central determinate of success in the self-management of chronic illnesses. Nevertheless, the extent to which self-efficacy is in fact a significant independent variable relating to self-management capabilities in the overall population remains unclear. So too, it may be suggested, does the degree to which high levels of observed self-efficacy are a direct cause, rather than a consequence, of coping well with ill health. Following on from this the lack of carefully reported data on relationships between social positioning (social class, gender and ethnicity) and self-efficacy relating to chronic condition self-management is, from a sociological standpoint, a matter of concern. Bandura's (1986) own discussion of self-efficacy has recognised structural constraints over behaviour.

Over-enthusiastic interpretations of evidence such as that produced by Lorig and her colleagues could have distorting effects on policies. As a matter of principle, it is important to guard against the development of a health service/policy culture in which political pressures rather than robust, scientifically valid, evidence define 'what works'. At worst, 'raising self-efficacy' and/or providing 'EPP therapy' might become uncritically seen as a psychological 'magic bullet' for promoting better use of health services and healthier lifestyles.

It is understandable that policy makers might hope for a psychologically based 'short cut' to achieving the sorts of public health and financial gain outlined in the 2004 Wanless report's 'fully engaged' scenario. Ministers and civil servants may naturally wish to believe in the potential advantages of such an intervention, not least because of the political and economic costs likely to be associated with more radical societal changes. But uncritically pursuing what may in actuality be a chimera could have unwanted consequences.

Relevant risks are to a degree illustrated by the fact that in the US earlier politically inspired initiatives aimed at promoting greater self-esteem – which it was hoped would improve educational outcomes and reduce crime levels – are now regarded as having been ill advised (Mecca *et al.* 1989, Baumeister *et al.* 2005). In fact, promoting increased self-esteem can in some circumstances encourage antisocial behaviours. Paradoxical results might also be associated with a raised sense of self-efficacy, at least in some population groups. Gender may prove a particularly relevant variable to explore further in this area, not least because men are much less frequent attendees of self-management groups than women.

Other unintended outcomes that naïve interpretations of the research base underpinning the Expert Patients Programme might generate raise a number of other concerns. We mention here only those that seem most salient. First, it may create an environment in which unfairly critical normative judgements are passed on individuals with chronic illnesses who 'fail' to display approved levels of self-efficacy, perseverance and independence. Sociologically, it would be hazardous and potentially unethical to extrapolate from observations of how some individuals or communities cope successfully with health challenges in ways which prescribe how others *ought* to behave.

Secondly, the emphasis on self-management may allow or facilitate harmful withdrawals of services, because they are mistakenly seen as no longer needed to meet the needs of 'empowered/expert' patient populations. It is possible, for instance, that proposals such as those in the 2004 *NHS Improvement Plan* for the majority of NHS users with long-standing

conditions could eventually lead to undesirable reductions in some user groups' direct access to – say – GPs, with uncertain long-term consequences.

Thirdly, there may be a reduction in professional and/or political awareness of the importance of the broad social/material determinates of (public) health. This might again be driven by inaccurate perceptions of the extent to which voluntary changes in individual cognitions and behaviours can result in health gain. There may also be a risk that focusing attention on a specially funded 'lay-led' NHS self-management support service could serve to reduce pressures on mainstream health professionals to understand adequately the work of individuals such as Bandura and Lorig, and stop practising in ways which may undermine the self-confidence of 'their patients'.

It would be alarmist to exaggerate the likelihood of such theoretical hazards causing substantive harm, and wrong to deny the common-sense appeal of the EPP initiative. Those responsible for its introduction and development deserve an informed response. In a climate of audit and accountability it is understandable that the CMO is currently challenging medical and other professional attitudes in ways which will increase respect for people using the health service, and enhance the latter's abilities to cope with adversity. It would however be unfortunate if such intentions were marked by an inadequate understanding of the complex ways patients relate with health professionals at present, or misperceptions relating to how behavioural change at a population level can best be achieved. It is relevant to note that while the work of Lorig and her colleagues gave emphasis to issues such as fostering social support, enhancing personal networks and the avoidance of problems as a means of coping, their later discourse appears to have become more narrowly focused on a psychological approach.

This may be partly explicable given the US health cultural context and the performance expectations of organisations financing self-management programmes in America. But in relation to the EPP and the future of public health policy and practice in the UK (at least, in England and Wales) such observations raise the possibility of a gradual slide towards an unduly one-sided approach. This could place too much emphasis on individual choice and responsibility, and too little on social solidarity and collective provision.

### **Conclusions – professionalism, service-user empowerment and healthcare delivery in the 21<sup>st</sup> century**

The establishment of the EPP in the English NHS can be seen as a single step in a much larger social process that might broadly be termed care transition. This is linked to the demographic and epidemiological transitions that have increased the prevalence of chronic illness throughout the world. They have also been associated with major societal changes in areas ranging from the social inclusion of people with physical or mental disabilities to women's access to birth control and allied services. Assuming – perhaps optimistically – that new change drivers, such as global warming and international conflict, do not radically disrupt the public health progress recorded over the past two centuries in this country and elsewhere, this long-term process of social adaptation will continue into the future.

For doctors, nurses, pharmacists and other health professionals, care transition has already created new environments in a variety of fields. For instance, the establishment in the Victorian period, and closure in the second Elizabethan era, of asylums for people with mental illnesses and learning difficulties (followed by attempts to integrate their health and social care more fully into normal daily life) has had significant implications for many patients and practitioners.

As knowledge-based occupations, rather than employment involving manual labour, have increasingly become the norm, and as average levels of income and education have risen, health professionals have had to accept significant changes in their social status relative to those for whom they care. This has for some created problems and distress. New approaches to health and social care quality improvement and assurance may also have appeared deeply threatening (McKinlay and Marceau 2002, Edwards *et al.* 2002).

The new social context associated with population ageing has, however, also brought new and, for some professionals, welcome opportunities for reforming paternalistic relationships in healthcare, and enabling service providers to work in closer partnership with health service users (Charles *et al.* 1997, Coulter 2002). Seen in this light, the introduction of the Expert Patients Programme can again be regarded as part of a much larger trend that is demanding change throughout medicine and allied fields, including – for example – pharmacy practice. Promoting concordance in medicine taking – the genesis of which was associated with an acceptance that today many people will not, without being given good reason, comply with pharmacists' or doctors' instructions to take treatments – reflects a growing professional awareness of the importance of respecting patients' beliefs and decisions and developing 'evidence-based' practice. Whilst some aspects of these policies may be seen as rhetorical devices employed by politicians and professional élites for essentially sectional reasons (Armstrong 2002), they are nevertheless associated with real changes.

One potentially important conclusion to draw, therefore, is that although to many NHS staff the EPP may at present seem to be of only marginal importance, the thinking upon which it is based is likely to influence the future delivery of all high-quality medical, pharmaceutical and nursing care. The research reviewed in this paper suggests that – notwithstanding their popularity among some groups, and possible cost advantages – lay-led interventions may in fact have little or no unique capacity to promote increased self-efficacy and enhanced chronic illness self-management. Hence, if care transition is to be meaningful, finding ways of adapting mainstream professional practice to facilitate more patient confidence in health- and illness-related problem solving needs to be given greater priority than at present. The danger that the EPP as currently structured might inhibit rather encourage such developments should be recognised, and action taken to offset this danger.

In the UK as a whole, enhanced professional involvement in the promotion of self-management could be beneficial to all sides interested in health and healthcare improvement. Yet even if this view is accepted, efforts further to promote chronic disease self-management will by themselves be unlikely dramatically to improve healthcare outcomes, or cut its costs.

Even with the introduction of sophisticated new information and support services such as NHS Direct, it is not clear that enhanced 'patient empowerment' will necessarily serve to reduce overall demand for hospital care. Neither will it automatically facilitate the acceptance of relatively impersonal services in place of the individual relationships characteristic of (albeit sometimes idealised models of) traditional family/general practitioner care.

Many other areas could be developed in future work. For instance, greater emphasis could be put on investigating the possible interplay between the supply of EPP and CDSM course places for individuals with chronic conditions and initiatives aimed at supporting their families. (See, for example, Kalra *et al.* 2004). In addition, awareness of the benefits of extending the capacity of the NHS to promote self-management skills could be examined alongside the place of the voluntary sector in facilitating self-help. In some areas (like smoking cessation 'quit line' provision), extensions of 'NHS-branded' services have arguably been achieved at the expense of voluntary-sector-led arrangements. Recent innovations in 'patient and public involvement' can be seen to have been imposed rather than negotiated,

and have muted rather than facilitated informed independent comment during a time of extensive health service change. One option for the future – that could perhaps offset any perception that the true purpose of the EPP is to limit rather than support appropriate health service use – might be to investigate the extension of independent voluntary-sector organisations in the publicly funded provision of chronic disease self-management programmes.

The final points to make here, however, relate to the interface between medical sociology and health psychology and the contributions that both disciplines can make to improving the wellbeing of people affected by chronic illnesses. Notwithstanding the questions raised in this paper, psychological insights such as those on the linkages between self-efficacy and problem solving in chronic disease self-management can be useful for individuals in improving health outcomes. Psychological treatments and allied interventions may enable individual thinking to be changed, and help to enhance adaptation to the challenges of living with a long-term illness. More carefully designed research could throw new light on such processes in the future.

By contrast, sociology offers understandings about the social contexts in which individuals operate. The practical value of this may be less immediately apparent than is the case with ‘products’ such as the ASMP and the CDSMP. Yet sociological investigations have described the strategies that lay people adopt in order to live with disabilities and long-term health problems. They provide insight into how patterns of social interaction, the demands of everyday life and wider social variables influence choices and actions. Sociological research has also revealed the importance of narratives in shaping the experience of illness, and maintaining personal and group self-identity.

There are often tensions between psychological and sociological approaches. Yet, in practice, there are also substantial overlaps between them (indeed, as noted, elements of Bandura’s work (1986) have a strongly social orientation). Further, for most lay people such interdisciplinary disputes are merely ‘academic’. This is perhaps especially likely to be so for those facing major health problems. Their main interests lie in having affordable access to timely and effective treatments and support services, based on the best possible appreciation of the options available to them as individuals in society.

Hopefully, future work aimed at drawing together a comprehensive and robust evidence base on chronic illness and its consequences will help permit and guide further progress in care transition. The end point of this last is to enable increasing proportions of the population living with long-term conditions to do so as successfully as possible, given the realities of their personal and social situations.

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## References

- Acheson, D. (1998) *Independent Inquiry into Inequalities in Health*. London: The Stationery Office.
- Anderson, R. and Bury, M. (eds) (1988) *Living with Chronic Illness: the Experiences of Patients and their Families*. London: Unwin Hyman.
- Armstrong, D. (2002) Clinical autonomy, individual and collective: the problem of changing doctors’ behaviour, *Social Science and Medicine*, 55, 10, 1771–7.
- Bandura, A. (1986) *Social Foundations of Thought and Action*. New Jersey: Prentice Hall.

- Bandura, A. (1994) Self-efficacy. In Ramachandran, V.S. (ed) *Encyclopedia of Human Behavior*. New York: Academic Press.
- Barlow, J.H., Turner, A.P. and Wright, C.C. (1998) Long-term outcomes of an arthritis self-management programme, *British Journal of Rheumatology*, 37, 1315–19.
- Barlow, J.H., Turner, A.P. and Wright, C.C. (2000) A randomized controlled study of the Arthritis Self-Management Programme in the UK, *Health Education Research*, 15, 6, 665–80.
- Barnes, C. and Mercer, G. (2003) *Disability*. Cambridge: Polity Press.
- Battersby, M. (2004) The Australian Sharing Health Care Program – education for clinicians and consumers. In Neilson E. (ed) *Perspectives on the Expert Patient*. London: The Royal Pharmaceutical Society of Great Britain.
- Baumeister, R.F., Campbell, J.D., Krueger, J.I. and Vohs, K.D. (2005) Exploding the self-esteem myth, *Scientific American*, 292, 70–7.
- British Household Survey (2001) www.iser.essex.ulsc/bhps.
- Bunker, J. (2001) *Medicine Matters After All: Measuring the Benefits of Medical Care, a Healthy Lifestyle and a Just Social Environment*. London: The Nuffield Trust.
- Bury, M., Newbould, J. and Taylor, D. (2005) A review of the current state of knowledge regarding lay-led self-management of chronic illness. Paper in preparation, London: National Institute of Health and Clinical Excellence.
- Bury, M. (1997) *Health and Illness in a Changing Society*. London: Routledge.
- Bury, M. (2001) Illness narratives: fact or fiction, *Sociology of Health and Illness*, 23, 3, 263–85.
- Cayton, H. (2005) The flat-pack patient? Co-creating health and health services. Paper presented at *World Health Congress, Paris*.
- Charles, C. Gafni, A. and Whelan, T. (1997) Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango), *Social Science and Medicine*, 44, 5, 681–92.
- Charmaz, K. (2000) Experiencing chronic illness. In Albrecht, G.L. Fitzpatrick, R. and Scrimshaw, S.C. (eds) *The Handbook of Social Studies in Health and Medicine*. London: Sage.
- Command 3807. *The New NHS: Modern. Dependable.*
- Command 4386. *Saving Lives: Our Healthier Nation.*
- Command 4818-1. *The NHS Plan. A Plan for Investment: A Plan for Reform.*
- Command 6374. *Choosing Health: Making Healthy Choices Easier.*
- Cooper, J. (2001) *Partnerships for Successful Self-Management*. The Living with Long-term Illness (Lill) Project Report. London: The Long-term Medical Conditions Alliance.
- Cooper, J. (2004) *From Patient to Person: the Living Well Report*. London: The Long-term Medical Conditions Alliance.
- Corbin, J. and Strauss, A. (1988) *Unending Work and Care: Managing Chronic Illness at Home*. San Francisco: Jossey Bass.
- Corbin, J. and Strauss, A. (1991) Comeback: the process of overcoming disability. In Albrecht, G. and Levy, J. (eds) *Advances in Medical Sociology*, Volume 2. Greenwich CT: JAI Press.
- Coulter, A. (1999) Paternalism or partnership? Patients have grown up – and there's no going back, *British Medical Journal*, 319, 719–20.
- Coulter, A. (2002) *The Autonomous Patient: Ending Paternalism in Medical Care*. London: The Stationery Office.
- Department of Health (2001) *The Expert Patient: a New Approach to Chronic Disease Management for the 21<sup>st</sup> Century*. London: Department of Health.
- Department of Health (2003) *Improving Chronic Disease Management*. London: Department of Health.
- Department of Health (2004) *The NHS Improvement Plan: Putting People at the Heart of Public Services*. London: Department of Health.
- Donaldson, L. (2003) Expert patients usher in a new era of opportunity for the NHS, *British Medical Journal*, 326, 1279–80.
- Edwards, N., Kornacki, M.J. and Silversin, J. (2002) Unhappy doctors: what are the causes and what can be done? *British Medical Journal*, 324, 835–8.
- EPP Evaluation team (2005) *Process Evaluation of the EPP-Report II*. National Primary Care Research and Development Centre, University of Manchester.

- Frank, A.W. (1995) *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: University of Chicago Press.
- Fu, D., Fu, H., McGowan, P. *et al.* (2003) Implementation and qualitative evaluation of chronic disease self management programme in Shanghai, China: a randomized controlled trial, *Bulletin of the World Health Organization*, 81, 3, 174–82.
- Gooberman-Hill, R., Ayis, S. and Ebrahim, S. (2003) Understanding long-standing illness among older people, *Social Science and Medicine*, 56, 2555–64.
- Graham, H. (ed) (2000) *Understanding Health Inequalities*. Buckingham: Open University Press.
- Gray, A. (ed) (2001) *World Health and Disease*. Buckingham: Open University Press.
- Griffiths, C., Motlib, J., Azad, A., Ramsay, J., Eldridge, S., Khanem, R., Munni, R., Garrett, M., Barlow, J., Turner, A. and Feder, G. (2005) Expert Bangladeshi patients? Randomised controlled trial of a lay-led self management programme for Bangladeshis with chronic disease, *British Journal of General Practice*, 55, 520, 831–7.
- Ham, C., York, N., Sutch, S. and Shaw, R. (2003) Hospital bed utilisation in the NHS, Kaiser Permanente and the US Medicare programme: analysis of routine data, *British Medical Journal*, 327, 1257–60.
- Hutt, R., Rosen, R. and McCauley, J. (2004) *Case Managing Long Term Conditions: What Impact does it Have in the Treatment of Older People?* London: King's Fund.
- Jaffri, T., Jones, R., Taylor, D. and Wakeling, M. (2003) *Future Partnerships. Primary Care in 2020?* London: School of Pharmacy, University of London.
- Jones, R. (2005). Personal communication.
- Kalra, L., Evans, A., Perez, I., Melbourn, A., Patel, A., Knapp, M. and Donaldson, N. (2004) Training carers of stroke patients: randomised controlled trial, *British Medical Journal*, 328, 1099–2004.
- Kelly, M. and Field, D. (1996) Medical sociology, chronic illness and the body, *Sociology of Health and Illness*, 18, 241–57.
- Kelly, M.P. and Millward, L.M. (2004) Identity and Illness. In Kelleher, D. and Leavey, G. (eds) *Identity and Health*. London: Routledge.
- Kennedy, A., Gately, C. and Rogers, A. (2003). The process of implementing a self-management policy within the English National Health System. Paper presented at the National Chronic Condition Self-Management Conference, Australia.
- Kennedy, A., Gately, C., Rogers, A. and EPP Evaluation Team (2004) Assessing the Process of Embedding EPP in the NHS: Preliminary Survey of PCT Pilot Sites. National Primary Care Research and Development Centre, University of Manchester, UK.
- Lawton, J., Peel, E., Parry, O., Araoz, G. and Douglas, M. (2005) Lay perception of type 2 diabetes in Scotland: bringing health services back in, *Social Science and Medicine*, 60, 1423–35.
- Lorig, K. (2002) Partnerships between expert patient and physicians, *The Lancet*, 359, 814–15.
- Lorig, K. and Holman, H. (2000) Self-management education: context, definition and outcomes. Paper presented to the Chronic Disease Self-Management Conference, Sydney, Australia, August 2000.
- Lorig, K., Lubeck, D.R., Kraines, R.G., Seleznick, M. and Holman, H.R. (1985) Outcomes of self-help education for patients with arthritis, *Arthritis and Rheumatism*, 28, 6, 680–5.
- Lorig, K., Feigenbaum, P., Regan, C., Ung, E., Chastain, R.L. and Holman, H.R. (1986) A comparison of lay-taught and professional-taught arthritis self management courses, *Journal of Rheumatology*, 13, 4, 763–7.
- Lorig, K., Mazonson, P.D. and Holman, H. (1993) Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs, *Arthritis and Rheumatism*, 36, 439–46.
- Lorig, K., Sobel, D.S., Stewart, A.L., Brown, B.M., Bandura, A., Ritter, P., Gonzalez, V.M., Laurent, D.D. and Holman, H.R. (1999) Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization, a randomized trial, *Medical Care*, 37, 1, 5–14.
- Lorig, K.E., Ritter, P., Stewart, A.L., Sobel, D.S., Brown, B.W., Bandura, A., Gonzalez, V.M., Laurent, D.D. and Holman, H.R. (2001) Chronic disease self-management program, 2-year health status and health care utilization outcomes, *Medical Care*, 39, 11, 1217–23.

- Lorig, K.R., Ritter, P.L., Laurent, D.D. and Fries, J.F. (2004) Long-term randomized controlled trial of tailored-print and small-group arthritis self-management interventions, *Medical Care*, 42, 4, 346–54.
- McKinlay, J.B. and Marceau, L.D. (2002) The end of the golden age of doctoring, *International Journal of Health Services*, 32, 2, 379–416.
- Mecca, A.M., Smelser, N.J. and Vasconcellos, J. (1989) *The Social Importance of Self-esteem*. Berkeley: University of California Press.
- Newman, S., Steed, L. and Mulligan, K. (2004) Self-management interventions for chronic illness, *The Lancet*, 364, 1523–37.
- ONS (2002a) *Social Trends 33*. London: The Stationery Office.
- ONS (2002b) *Living in Britain: the General Household Survey*. London: The Stationery Office.
- Patrick, D. and Peach, H. (eds) (1989) *Disablement in the Community*. Oxford: Oxford Medical Publications.
- Pollock, A.M. (2004) *NHS Plc: The Privatisation of our Health Care*. London: Verso.
- Prior, L. (2003) Beliefs, knowledge and expertise: the emergence of the lay expert in medical sociology, *Sociology of Health and Illness*, Silver Anniversary Issue, 25, 41–57.
- Roland, M., Dusheiko, M., Gravelle, H. and Parker, S. (2005) Follow up of people aged 65 and over with a history of emergency admissions: analysis of routine admission data, *British Medical Journal*, 330, 289–92.
- Sen, A. (2002) Health: perception versus observation, *British Medical Journal*, 324, 860–1.
- Sobel, D.R., Lorig, K.R. and Hobbs, M. (2002) Chronic disease self-management program: from development to dissemination, *The Permanente Journal*, 6, 2, 15–22.
- Strauss, A.L. (1975) *Chronic Illness and the Quality of Life*. St Louis: Mosby.
- Taylor, D.G. and Bloor, K. (1994) *Health Care, Health Promotion and the Future General Practice*. London: Nuffield Provincial Hospitals Trust.
- Wanless, D. (2002) *Securing our Future Health*. London: HM Treasury.
- Wanless, D. (2004) *Securing Good Health for the Whole Population*. London: HM Treasury.
- Weingarten, S.R., Henning, J.M., Badamgarav, E., Knight, K., Hasselblad, V., Gano, Jr, A. and Ofman, J.J. (2002) Interventions used in disease management programmes for patients with chronic illness – which ones work? Meta-analysis of published reports, *British Medical Journal*, 325, 925–33.
- Whitehead, M., Diderichsen, F. and Burstrom, B. (2000) Researching the impact of public policy on inequalities in health. In Graham, H. (ed) *Understanding Health Inequalities*. Buckingham: Open University Press.
- Wilson, T., Buck, D. and Ham, C. (2005) Rising to the challenge: will the NHS support people with long term conditions? *British Medical Journal*, 330, 657–61.
- Wright, C.C., Barlow, J.H., Turner, A.P. and Bancroft, G.V. (2003) Self-management training for people with chronic disease: An exploratory study, *British Journal of Health Psychology*, 8, 464–76.