

Masterclass Paper

Advancing the Expert Patient?

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The self-management of long-term conditions undertaken by people in their own homes has been attributed with increasing importance in health care policy. Interventions based on self-skills training have been introduced as a means of promoting and increasing levels of self-care practises in the population which have been informed by psychological models and concepts of change such as in the case of the national policy of the Expert Patients Programme (EPP) self-efficacy. Evidence to date suggests modest or equivocal effectiveness and there may be a number of reasons for this. One of the reasons is a failure to give due attention to the perspectives and work that patients themselves undertake in self-management interventions. Whilst the notion of an Expert Patient conveys a sense of what a new health policy centred on long-term condition management hopes to achieve, an important corollary is understanding the conditions necessary to accommodate and embed new techniques in the routine elements of illness 'work' undertaken by patients living with a long-term condition. This paper explores the health policy context of self-management, including the evidence and adequacy of the organizing concepts and outcomes associated with the EPP, and suggests that a greater focus on illness work and the social and domestic contexts is required in future innovation and research in the area of long-term condition management.

Key words: Expert Patients; patient work; policy; self-management

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Introduction

Self-care support is a central tenet in contemporary health care policy for chronic illness and the Expert Patient is associated with one aspect of dealing with chronic illness – the adoption of chronic disease management and self-skills training through health policy implementation. The aims of this paper are threefold. First, to critically consider the changing location, images and expectations behind the current focus on state sponsored support for self-management. Secondly, to explore the evidence and limitations of contemporary policy for self-care

support through focusing on the Department of Health for England's *Expert Patients Programme* (EPP), and the adequacy of its organizing concepts and outcomes – particularly its focus on self-efficacy and notion of the Expert patient-hood. Thirdly, I want to argue for an agenda within chronic disease self-management, which brings into sharper focus the notion of illness work for progressing research and the implementation of self-care support in future primary care practice.

Origins: self-management as a lay activity outside of the health care system

Self-care refers broadly to a range of activities that patients undertake for themselves in managing

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illness. This includes negotiating one's way through the health service, the use of skills, information, technology and resources, mobilising and drawing on social networks and the use of guided self-management programmes devised by professionals.

Policy, which explicitly advocates self-care support¹ for people with a chronic condition, is a recent phenomenon. However, the idea that people facing living life with a long-term condition should practice self-care is by no means new. Despite the increasingly specialized roles assumed by health professionals and expansion of treatments designed to ameliorate the symptoms of chronic illness and delay mortality, how chronic illness is managed has been and remains the province of lay people. Surveys conducted at different points in time have shown that only a small proportion of ill health ever reaches the health care system and the reasons for the non-presentation of illness to general practice is because a significant proportion of ailments are managed by individuals without recourse to professional care (Wadsworth *et al.*, 1971; Rogers and Nicolaas, 1998).

Sociological studies have drawn attention both to the way in which self-management constitutes a ubiquitous, taken for granted, intuitive and routinized set of activities embedded in the everyday life of communities (Robinson, 1971), and the specific aspects of the experience and work of managing a chronic illness. In-depth studies suggest that along with disruption to the normal life course (Bury, 1982) and changes to self perception, the sequela of being diagnosed with a chronic illness necessarily involves adaptation to the social world through the re-definition of peoples' competence as social actors (Gerhardt, 1989), the protection of self-identity from the threat of stigma and, of most relevance, to understanding self-management, developing and drawing upon various coping mechanisms, strategies and styles of managing which individuals develop over time (Bury, 1991). From this vantage point, self-management is represented by the mobilization of resources and the maintenance of normal activities and relationships (family, friends and occupations) in the face of an

altered situation. The notion of 'strategy' captures the practical steps taken in order to mobilize resources and minimize problems in everyday life (Locker, 1983). 'Style' has been used to denote the various symbolic ways in which people respond to and present their illness, both to themselves and others (Radley and Green, 1987).

Self-management activity has also been expressed in a collective form as the orientated actions of new health social movements (NHSMs). NHSMs are networks of mutually supportive people with a shared collective identity and ambivalence about the health care system with a motivation and orientations to civil rights (Rogers and Pilgrim, 1991).²

This history of lay peoples' long-standing involvement with self-management is reflected only marginally within recent policy making about self-management. Indeed, the informal health care system remained invisible and excluded from the agendas of policy makers until the late 1990s. With the adoption of self-management and its incorporation into official UK health policy both the radical/oppositional and collective aspects of bottom up patient action seems to have been discarded. Rather a new agenda has been configured by a series of official policy documents and reviews which centre on the notion of supporting self-care.

State sponsored self-management from the 1990s on and the emergence of the Expert Patients Programme

Ideas generated in policy circles immediately prior to the election of a New Labour administration in 1997 in the UK included self-care skills training, proposals for a national telephone help-line and supporting people in the community. The key 1997 *New NHS White Paper* (Department of Health, 1997) outlined a government commitment to supporting people to care better for themselves, and the subsequent 2000 *NHS Plan* cited self-care as one of the five key building blocks of the future NHS (Department of Health, 2000). However, the new approach to self-care began to

¹ Self-care support is the facility that healthcare and social-care services provide to enable individuals to take better care of themselves and self-care support.

² Examples include those involved with mental health issues (the hearing voices network (<http://www.hearing-voices.org/>)) and feminist critiques of traditional medicine (The Boston Women's Health Book Collective, 2005).

gain real momentum with the New Labour government's 1999 White Paper, 'Saving Lives, Our Healthier Nation' (Department of Health, 1999). This paper set out to demonstrate how government proposed 'to save lives, promote healthier living and reduce inequalities in health'. The document pointed out that 'everybody should try to look after themselves better, by not smoking, taking more exercise, drinking less and eating more sensibly' (preface).

Subsequently, along with concern for the health status of the nation, a direct link to cost and the need to manage demand was made in the first Wanless report (Wanless, 2002). This marked out a 'fresh page' approach to the concordat between medical care, the patient and the state, and noted the importance of self-care in general. However, its relevance was principally directed to long-term conditions by placing self-care at the centre of the 'fully engaged' scenario, which was also significantly cheaper than two alternative scenarios – 'steady progress' and 'slow uptake'. The fully engaged scenario envisaged people taking more control of their health and illness by making better use of a health service that was technologically advanced but which would mean a more efficient and effective use of NHS resources. Furthermore, in the fully engaged scenario, Wanless suggested that the consequences of non-uptake of self-management were serious, that is to say:

Fully engaged and active patients benefit not only as individuals. My inquiry showed that encouraging and supporting self-care was one of a number of actions which could potentially save the economy billions of pounds... patients remain far from fully engaged in their own care; opportunities are being lost and inequalities reinforced. (http://www.picker-europe.org/Filestore/PressReleases/PAS_press_release_FINAL.pdf)

A number of other initiatives followed focussing on the implementation of these aspirations. In 2003, the Chief Nursing Officer was appointed as the Department of Health's Director for self-care and in 2004, the *NHS Improvement Plan* identified self-care as one of the new National Standards (D10) 2004 (Department of Health, 2004b). The 'Choosing Health' White Paper planned for 'health trainers' (Department of Health, 2004a), which was followed by the production of Guidance

documents in 2005 entitled 'Self Care – A Real Choice' (Department of Health, 2005). Another key White Paper titled 'Our health, our care, our say...' 'Supporting people with long-term conditions to self care', followed in 2006 (Department of Health, 2006).

Expectations as to what the new policy could deliver were high and the benefits of supporting self-care were certainly promoted as substantial by its advocates. Benefits identified in these policy documents included health and system related outcomes which included increases in life expectancy: better control over symptoms, reductions in pain, anxiety and depression levels, improvement in quality of life with greater independence, days off work were estimated to reduce by up to 50% and an increase in social capital. Explicit implications for the care system have been identified as improved quality of consultations, a reduction in general practitioner visits of between 40% and 69% and hospital admissions by up to 50%. Claims were also made that hospital length of stay could reduce, as could the number of days in hospital (by as much as up to 80%), out-patient visits (by between 17% and 77%) and accidents and emergency visits (by 54%), with medication intake, for example steroids, reduced and medicines 'compliance' being improved by 30% (http://209.85.229.132/search?q=cache:fv0A2XuyKeEJ:www.ich.ucl.ac.uk/cypph/downloads/learning/Self_Care_RealChoice.pdf).

These broad-ranging expectations were funnelled in the first instance to one key initiative, the EPP, which was initiated by the Department of Health in 2001 (Department of Health, 2001). The Chief Medical Officer who set up a task force to develop the EPP included representation from voluntary sector organizations including the *Long Term Medical Conditions Alliance* and *Arthritis Care* who had run self-care skills training courses in the UK in the early 1990s and had subsequently promoted and disseminated the training which formed the core of the EPP through a volunteer work force. In the next few years (notably, 2003–07) this programme was brought on stream in primary care trusts (PCTs) in England.

An array of aims was included in the original EPP training course which included changing the culture of the NHS to be more receptive to self-care and professional training. However, most emphasis was placed on the dissemination of

skills-training which was a programme modified to run as a generic programme based on the *Chronic Disease Self-Management Programme* developed at Stanford University (Lorig *et al.*, 1999). It comprised six weeks of 2.5-hour-long sessions, which were delivered by trained volunteers/paid lay trainers and focussed on the uptake and regular use of a set of generic skills. The six-week EPP training course operated on an open referral basis available to anyone with a long-term condition and was designed to be delivered by trained volunteers or paid trainers through health and social care organizations or community voluntary organizations licensed to deliver the course. In terms of specific skills, the content of the course was orientated to 'Expert Patients' learning relaxation, better breathing, healthy eating and nutrition, exercise, how to build levels of fitness, flexibility and strength, how to communicate more effectively, making informed choices, dealing with anger, fear, frustration, isolation, fatigue and depression, using problem solving skills, making plans and working with health care professionals.

The effectiveness of the Expert Patients Programme

Prior to its introduction in England, the Stanford training programme had been subjected to a number of studies, some of which used randomized controlled trials and were generally large and well conducted. Nonetheless, whilst demonstrating high internal validity the scope of such studies were limited in the extent to which they undertook economic analysis. Additionally no such study had been conducted in the UK so there was a question of establishing external validity (Kennedy *et al.*, 2007a; 2007b; 2007c) and the interest in generic programmes was a particular focus of the UK policy, and the existence of NICE (National Institute for Clinical Excellence). These considerations generated a political necessity of conducting trials on all large NHS interventions which are destined for national roll out in the NHS.

The effectiveness of the EPP was tested in a trial alongside a range of other studies which formed a national evaluation conducted by the NPCRDC (National Primary Care Research and Development Centre). The outcomes used in the trial indicated that the training did have some

effects. In terms of primary outcomes, this included a medium effect on peoples' self-efficacy to undertake self-management, a small effect on energy (a marker of health status) and little effect on the overall routine utilization of health services. There were some small improvements in secondary outcomes, which included improvements to social role, emotions, health distress, exercise, relaxation, partnership working between patients and professionals (Kennedy *et al.*, 2007a; 2007b; 2007c). The programme was found likely to be cost effective with the intervention group showing better EQ5D scores (0.020 QALY (quality adjusted life years) gain) and were found to have reduced costs, estimated to be about £27 per patient (Richardson *et al.*, 2008). UK trials carried out at about the same time showed similar results (eg, Griffiths *et al.*, 2007). Notwithstanding the positive indications, given the high expectations of self-management policy in changes to behaviour, health status and utilization, these results at best delivered modest results falling short of those anticipated by EPP advocates and policy makers. This modest record of achievement is reinforced when placed in the context of implementation and a fine-grained exploration of the meaning of change. A process evaluation of the implementation of the programme showed that whilst there were few PCTs which had not implemented the policy (Lee *et al.*, 2006), there were nonetheless substantive difficulties in implementation (Kennedy *et al.*, 2005).

On the face of things subjectively, some recruits viewed EPP attendance as a positive, even life changing, experience. On the EPP website a volunteer tutor describes attendance on the course as life changing:

...the spark that caused a **revolution** in my life: a physical and emotional turn-around. I learned to breathe again; learned to stop beating myself up ... The EPP is a guide out of the quagmire and maze of depression. Here I am now, 1000 times better, 500 times stronger. My life has been **transformed** over the last two years and I can say with absolute certainty that I owe it all to the Expert Patients Programme.

However, doubts about the ability to reach those most likely to benefit raised questions regarding its appeal to wider population groups.

Moreover, closer scrutiny of the underlying ethos of the programme raises a number of questions about its underlying ethos.

The problem with self efficacy and psychological determinism

I wish to point to two problems with the essential psychological assumptions of the programme. The first is how a programme, which focuses on changes in self-efficacy, is able to deal with social needs and inequalities. The second relates more broadly to a problem with the presumptions in psychological theories of change underpinning self-management interventions more generally.

Sidelining social need

Self-efficacy is a construct referring to the strength of a person's belief in their purported capability to do a specific task or achieve a certain result (ie, manage symptoms or engage in self-help), and is viewed as being enhanced through a number of mechanisms, the most effective of which is considered to be 'performance attainment' (ie, actual experience of the success of actions). Self-efficacy is viewed as a mediating construct for behavioural change in the EPP because changes in health status and behaviour are thought to be mediated by changes in 'self-efficacy' (Bandura, 1977). It is clear that self-efficacy is a desirable attribute associated with long-term condition management and, as an outcome, was highly valued amongst the self-selected recruits of the EPP trial during its pilot phase (Richardson *et al.*, 2009).

However, the relevance of self-efficacy may be in danger of being overplayed when viewed in the context of other expected outcomes and experiences of patients. The emphasis placed on self-efficacy in reports of research and in the delivery of courses means that, unintentionally perhaps, it has moved from being viewed as a mediating construct to attaining the status of the most important patient outcome, bringing with it the marginalizing of other patient considerations. For example, a qualitative study found that some peoples' expectations and problems were not adequately dealt with by the course because the self-care skills training programme prioritized

improvements in self-efficacy and did not engage with patients' material and social needs (Kennedy *et al.*, 2007a; 2007b; 2007c). Moreover, the group dynamics which the EPP relies on may inadvertently encourage feelings of worthlessness and thus contribute to inequalities. Social comparisons, which group-based programs rely on for mediating self-efficacy, can have a negative effect if positive comparisons by individuals cannot be made (Gately, 2009). Being poor and ill brings with it the possibility of shame and insecurity that have the potential to be reinforced in group situations (Wilkinson, 2001).

More generally, I think that an over-reliance on psychological theories in self-management initiatives reinforces a narrow focus on specified attitudinal or behavioural processes to the exclusion of relevant and grounded aspects of living life with a chronic condition. The self regulatory model commonly referred to in the context of self-management draws upon the health belief model, which views *personal susceptibility* and *belief* in the benefits of action as influencing the likelihood of changing personal health action as outweighing any perceived costs and barriers (Anderson, 1995). Self-care interventions are commonly designed to move an individual from one psychological stage to the next – the transtheoretical model of behaviour change. Prochaska (1994) posits that people change behaviour through a number of stages: pre-contemplation, contemplation, preparation, action and maintenance. Leventhal and Nerenz (1985) have proposed a *self-regulation* model which addresses the impact of emotion, the time course of the disease and changes in the perception of threat over time. The patient is viewed as a 'problem solver', able to assess the risk of the disease and identify what actions to take when.

Notwithstanding an increasingly sophisticated focus on understanding beliefs (eg, recognizing affective and instrumental beliefs) and whilst, in theory, account is taken of an individual's socio-cultural context, prioritizing a focus on beliefs is limited as an explanatory framework. First, in self-management programmes where change does occur, it does not necessarily follow the theoretical stages of change incorporated into psychologically mediated models of health behaviour. Pre-defined notions of stages of change may mask or detract from a focus which views change differently. For example, in relation to the complexities of

patients, existing ways of behaving and responding to or adapting to chronic illness. Secondly, existing behaviour and activities in context are either ignored or viewed as maladaptive and requiring reform. This is perhaps not surprising given that notion of maladaptation in theories of 'planned action' are normative in the assumptions made about the desirability of swapping one behaviour for another (eg, smoking for non-smoking). Whilst such assumptions maybe appropriate in areas where the agenda is about changing deviant behaviour such as drug or alcohol addiction, the equation of this with chronic illness is a different matter. Since the origins of this and constructs like 'self-efficacy', 'self image' and 'self worth'³ (informing clinical and latterly health psychology) lie in deviancy theory, a deviant status may inadvertently transfer to candidates for self-management skills training – the poor self-manager lacking the properties needed to manage a chronic condition. Such imagery presents a stark contrast with the striving for normality that underlies most studies of the experience of chronic illness. Another facet of the recent trend in self-management which I want to turn to is the ideal type identity associated with being a good self-manager.

Expert patienthood and the imposition of an imagined identity

Policies concerned with health promotion have, for sometime, included appeals to normative lifestyles and desirable behaviours, which to an extent have been based on an ideology which blames or holds the individual responsible for his or her illness. However, whilst previous policies focused on what patients should do to maintain their health, the new policy approach to self-management is focused on what sort of *person* the patient should become. The required type of patient is one with attributes which resonates with the responsible citizen evident in recent policy associated with New Labour welfare policies (May, 2006). There has been a proliferation of terms representing an idealized self-managing individual ('empowered', 'autono-

mous', 'future', 'expert', 'activated', 'wireless', 'co-producer' or 'flat pack patient'). The ideal type notion of patienthood demands the capacity of being confident, in control, able to monitor and manage a condition, engage with technological innovations, whilst at the same time allowing constraints on the demands made on services. The 'flat pack patient' invests the ideal self-managing individual with the aptitudes or abilities of an active consumer. Cayton (2006) describes the desirable relationship between the self-managing patient and health services as follows:

Nearly everyone is familiar with self assembly furniture, particularly from the stores of the Swedish company IKEA. People buy a box containing all the necessary parts for say, a bookcase or a wardrobe or a table. They carry it home and assemble it themselves following the simple instructions (in seven languages) provided. Flat-pack furniture is a little bit of genius; the customer becomes a partner in the manufacturing process, saving the company time, money and of course space. In return, the company can reduce its prices and, believe it or not, many customers even enjoy building their own furniture – it is satisfying investing some personal time and effort in your home. It is definitely a win-win for companies and customers alike. a fully-engaged person is one who looks after themselves and makes choices with responsive health services to take responsibility for and to maintain and improve their own health. So are we in the process of producing flat-pack patients; patients who co-create their own health and health services? I want to argue that we are... (p. 288).

The notion of an activated patient is of particular salience since it forms the basis of a positive outcome of attending self-management courses such as the EPP. 'Activation' in self-management, is viewed as involving four 'developmental' stages: (i) coming to believe the patient's role is important, (ii) learning enough and developing enough confidence and knowledge necessary to take action and (iii) actually taking action to maintain and improve one's health (Hibbard *et al.*, 2007). However, evidence for the translation health and (iv) staying as healthy as possible (of adopting this 'activated' role and better health

³ Poor 'self-image' and self-worth originated in applications to deviant populations to engender delayed gratification, long-range planning and goal orientation (Sanders *et al.*, 2008).

outcomes) is at the very least equivocal. Recent research suggests that patients with or at risk of developing a chronic condition, who say they prefer to take an active role in their health care, are likely to be unhealthier than patients who prefer doctors to act in a more traditional way (Baldwin *et al.*, 2008). The EPP tended to attract and reinforce the norms of active and expert patients through attendance and subsequent conversion to a desired set of values (Rogers *et al.*, 2008).

Notwithstanding the clear identification of values with those who attend the course, the imposed imagery of the Expert Patient clearly lacks resonance and appeal to those it is aimed to win over. This is indicated by poor recruitment and attendance in key population groups. Simplistic formulations of what sort of person constitutes a good self manager is little more than the construction of wishful thinking when seen in the context of earlier studies, suggesting that protestations about what patients *should* be doing are well understood (Rogers *et al.*, 1997) but are not undertaken at the expense of maintaining a sense of coherence and control over everyday social and domestic roles or a sense of normal identity (Townsend *et al.*, 2006). Moreover, desirable identities and attributes can not simply be prescribed in a way which people follow. As Fox and Ward (2009) have recently pointed out identities can never be prior or essential. Whilst to a limited extent identities can be 'actively created' (Davies and Harré, 1988), the construction of ideal types of patienthood discussed above fail to acknowledge the role played by the social environments that individuals suffering from chronic illness inhabit and from which illness identities are mobilized and constructed.

Social identity theory in social psychology is predicated on the notion that cognitive identity formation is attributed with meaning only within prevailing contexts of power status and class (Brown and Lunt, 2002). Depending on context, condition and biography illness can have a major impact on an individual's identity (Bury, 1982). Alternatively, chronic illness as an anticipated biographical event may have little impact on a patient's identity merging with the 'normal' and 'inevitable' features of the life cycle (Sanders and Rogers, 2007). This complexity is lost in formulations of the ideal type self-manager. The absence of reference to the personal and social nuances of illness identity formation is even more

surprising given the claims that such initiatives are intended to be both patient-focused and centered. The dominant imagery of the ideal self-managing patient also hides the varied ways which people have found to manage their conditions in ways which fit with their ongoing domestic routines, sense of self and relationships to others. A set of alternative foci for understanding behaviour in context is required.

The missing notion of patient work

Clearly current research and the design of interventions does not pay due regard to the broader social and environmental context of people living with chronic conditions. There are a broad set of social scientific concepts informing population health which might help in filling the gap. The notion of *Therapeutic landscapes*: refers to 'places, settings, situations, milieus that encompass the physical, psychological and social environments associated with treatment or healing' which are reputed to have an enduring reputation for achieving physical, mental and spiritual healing (Kearns and Gesler, 1998). *Habitus* – the manner in which experience and action are structured by previous experiences provides a different window upon which to view living with a chronic condition as a function of acquired deeply ingrained habits. Bourdieu also refers to habitus as 'generative structures' which may be relevant for creating new environments for supporting self-management (Angus *et al.*, 2007). Illness management, as a collective rather than purely individualistic effort, has been illuminated by studies showing the combination of roles and relationships in managing illness within domestic settings (Gregory, 2005; Richardson, 2007).

Experience and identity have been important facets in understanding the change that occurs as a result of being diagnosed with a chronic illness (see above). Yet, taken on their own, they are limited for understanding and ultimately responding to patients' agendas and enactment of self-management because they do not engage with the sense and purpose underlying self-management practices that are medically conformist or deviant. I suggest that the notion of patient work and its place within a trajectory of long-term illness career make for better heuristic devices in a future agenda of research and implementation.

We know that patients' expectations and views of treatment vary according to the different stage in an illness career, and that illness career has a long tradition in sociology, which has utility for revealing changes in the adoption and accumulation of activities and practices that constitute the work of being ill and occur at different points in illness trajectories.⁴ In the EPP, a set of skills learned by the patient is viewed as a set of particular tasks addressing specific elements which are seen as the core of patient work – communicating with the doctor and action planning – packaged together in a formulaic way. The question of its fit with the actual everyday work that patients carry out in domestic and medical settings is more questionable. The latter requires a focus on the naturalistic ways that people undertake the work of being ill. Corbin and Strauss (1985) identified three types of interrelated domains of chronic illness work which are of utility:

- illness work (concerned with symptom management);
- everyday-life work (the practical tasks such as housework, caring, paid employment);
- biographical work (the reconstruction of the ill person's biography).

Although these three types are viewed as overlapping rather than mutually exclusive, this conceptualization of work permits the exploration of what people actually value and how much and in what contexts people tend towards one sort of work rather than another. For example, Townsend *et al.* (2006) found that whilst people with comorbid conditions use multiple techniques for managing symptoms overall, symptom management was not always the most important facet of patient work. Rather maintaining and preserving valued social roles, coherent identities and a 'normal life' (ie, managing the practical and moral dilemmas in living with chronic illness were more important). Additionally, an emphasis of everyday-life work may be the preference and reality for those who have assumed a more passive role in the doctor–patient relationship, seeing symptom management as the preserve of health professionals

⁴The notion of turning point (moments of a radical change in the expected course of a person's career) captures the way in which people can change a set of activities and changes in personal management via different routes.

and reinforced by the tendencies of health professionals to centre their own role on symptom management (MacDonald *et al.*, 2008). A number of different notions of work have been identified: articulation, delegated, redistributive, surveillance, diagnostic, emotional, invisible ('work that gets things back on track') interactional work, which are likely to be of utility in understanding the priorities of and existing work undertaken by patients, and relevant to understanding and judging the embedding and utility of self-management interventions.

Bringing back in health professionals

A final problem with the EPP which I wish to refer to here is the removal of the delivery of self-skills training from the service provision care and support provided by health professionals – particularly those working in primary care. Peer led training has its merits, most importantly that participants are able to relate to those delivering the course on the bases of a shared history of living with a long-term condition. Yet, there is currently little evidence that peer-led training is superior to that delivered by professionals. We know from research that interactions with professionals are central and it maybe that the nature of relationality needs to be more of a focus rather than the technology in self-care initiatives. Subjectively, people encountering self-help as an option find difficulty in limiting the professional role to that of facilitator (Pilgrim *et al.*, 2009). Indeed, a threat to existing positive relationships with professionals in primary care may be an unintended consequence of the lay versus professional dichotomy engendered by the promotion of peer leadership of the EPP. This is not to deny problems relating to the acknowledgement of patient agendas within health professional consultations. There is evidence of a tendency of professionals to marginalize patient agendas in self-management and, in particular, to ignore patients' own strategies for managing a chronic condition and to discount experiential knowledge (Wilson, 2001; Rogers *et al.*, 2005).

Conclusion

Historically, the concept of an Expert Patient has been used in a primary care context in a way

which denotes the need for a patient centred approach to the primary care consultation: 'A meeting between experts' is where patients are viewed as experts by virtue of the experience of living with an illness which placed them on an equal, if different, footing with health professionals in the consultation (Tuckett *et al.*, 1985). Reference to this original use of the term is notable by its absence in the more recently re-surfaced policy of the EPP where the term has a different meaning. Given the limitations of existing self-management programmes to engage large numbers of people with the potential to benefit, if self-management is to be a viable option in future chronic disease management within primary care, then a re-focusing on this original meaning and the illness work currently undertaken by patients should form a more prominent future focus of a systemic and grounded approach to self-management within primary care (Kennedy *et al.*, 2007a; 2007b; 2007c).

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References

- Anderson, R.** 1995: Revisiting the behaviour model and access to care: does it matter? *Journal of Health and Social Behaviour* 36, 1–10.
- Angus, J., Rukholm, E., Onge, R.S., Michel, I., Nolan, R.P., Lapum, J. and Evans, S.** 2007: Habitus, stress, and the body: the everyday production of health and cardiovascular risk. *Qualitative Health Research* 17, 1088–102.
- Baldwin, A., Cvengros, J., Christensen, A., Ishani, A. and Kaboli, P.** 2008: Preferences for a patient-centered role orientation: association with patient-information-seeking behavior and clinical markers of health. *Annals of Behavioral Medicine* 35, 80–86.
- Bandura, A.** 1977: Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review* 84, 191–215.
- Brown, S.D. and Lunt, P.** 2002: A genealogy of the social identity tradition: Deleuze and Guattari and social psychology. *British Journal of Social Psychology* 41, 1–23.
- Bury, M.** 1982: Chronic illness as biographical disruption. *Sociology of Health and Illness* 4, 167–82.
- Bury, M.** 1991: The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness* 13, 468–74.
- Causton, H.** 2006: The flat-pack patient? Creating health together. *Patient Education and Counseling* 62, 288–90.
- Corbin, J. and Strauss, A.** 1985: Managing chronic illness at home: three lines of work. *Qualitative Sociology* 8, 224–47.
- Davies, B. and Harré, R.** 1988: Positioning and person hood. In Harré, R. and van Langenhove, L., editors, *Positioning theory*. Oxford: Blackwell.
- Department of Health.** 1997: *The new NHS: modern, dependable*. London: The Stationery Office.
- Department of Health.** 1999: *Saving lives: our healthier nation White Paper and reducing health inequalities: an action report*. London: Department of Health.
- Department of Health.** 2000: *The NHS plan: a plan for investment, a plan for reform*. London: Department of Health.
- Department of Health.** 2001: *The Expert Patient: a new approach to chronic disease management in the 21st Century*. London: The Stationery Office.
- Department of Health.** 2004a: *Choosing health: making healthy choices easier*. London: The Stationery Office.
- Department of Health.** 2004b: *The NHS improvement plan: putting people at the heart of public services*. London: Stationery Office.
- Department of Health.** 2005: *Self care – a real choice: self care support – a practical option*. London: The Stationery Office.
- Department of Health.** 2006: *Our health, our care, our say: a new direction for community services*. London: Stationery Office.
- Fox, N.J. and Ward, K.J.** 2009: What are health identities and how may we study them? *Sociology of Health and Illness* 30, 1007–21.
- Gately, C.** 2009: The impact of illness experience and social context on the effect of a chronic disease self-management course: a mixed methodology approach. Unpublished doctoral thesis, University of Manchester.
- Gerhardt, U.** 1989: *Ideas about illness: an intellectual and political history of medical sociology*. New York: New York University Press.
- Gregory, S.** 2005: Living with chronic illness in the family setting. *Sociology of Health and Illness* 27, 372–92.
- Griffiths, Chris, Foster, G., Ramsay, J., Eldridge, S. and Taylor, S.** 2007: How effective are expert patient (lay led) education programmes for chronic disease? *British Medical Journal* 334, 1254–56.
- Hibbard, J.H., Mahoney, E.R., Stock, R. and Tusler, M.** 2007: Do increases in patient activation result in improved self-management behaviors? *Health Services Research* 42, 1443–63.
- Kearns, R.A. and Gesler, W.M.** 1998: *Putting health into place: landscape, identity, and well-being*. Syracuse, NY: Syracuse University Press.
- Kennedy, A., Rogers, A. and Gately, C.** 2005: Assessing the introduction of the expert patients programme into the NHS: a realistic evaluation of recruitment to a national lay-led self-care initiative. *Primary Health Care Research and Development* 137–48.
- Kennedy, A., Reeves, D., Bower, P., Lee, V., Middleton, E., Richardson, G., Gardner, C., Gately, C. and Rogers, A.**

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- 2007a: The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. *Journal of Epidemiology and Community Health* 61, 254–61.
- Kennedy, A., Rogers, A. and Bower, P.** 2007b: Support for self care for patients with chronic disease. *British Medical Journal* 335, 968–70.
- Kennedy, A., Rogers, A. and Crossley, M.** 2007c: Participation, roles, and the dynamics of change in a group-delivered self-management course for people living with HIV. *Qualitative Health Research* 17, 744–58.
- Lee, V., Kennedy, A. and Rogers, A.** 2006: Implementing and managing self-management skills training within primary care organisations: a national survey of the expert patients programme within its pilot phase. *Implementation Science* 1, 6.
- Leventhal, H. and Nerenz, D.** 1985: The assessment of illness cognition. In Karoly, P., editor, *Measurement strategies in health psychology*. New York: Wiley.
- Locker, D.** 1983: *Disability and disadvantage: the consequences of chronic illness*. London: Tavistock.
- Lorig, K.R., Sobel, D., Stewart, A., Brown, B., Bandura, A., Ritter, P., Gonzalez, V., Laurent, 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, 5–14.
- MacDonald, W., Rogers, A., Blakeman, T. and Bower, P.** 2008: Practice nurses and the facilitation of self-management in primary care. *Journal of Advanced Nursing* 62, 191–99.
- May, C.** 2006: Editorial: the hard work of being ill. *Chronic Illness* 2, 161–62.
- Pilgrim, D., Rogers, A. and Bentall, R.** 2009: The centrality of personal relationships in the creation and amelioration of mental health problems: the current interdisciplinary case. *Health* 13, 235–54.
- Prochaska, J.O.** 1994: *The transtheoretical approach: crossing traditional boundaries of therapy*, Krieger Pub Co.
- Radley, A. and Green, R.** 1987: Illness as adjustment: a methodology and conceptual framework. *Sociology of Health and Illness* 9, 179–207.
- Richardson, J.C.** 2007: Experiencing widespread pain in a family context: giving and receiving practical and emotional support. *Sociology of Health and Illness* 29, 347–65.
- Richardson, G., Bojke, C., Kennedy, A., Reeves, D., Bower, P., Lee, V., Middleton, E., Gardner, C., Gately, C. and Rogers, A.** 2009: What outcomes are important to patients with long term conditions? A discrete choice experiment. *Value in Health* 12, 331–39.
- Richardson, G., Kennedy, A., Reeves, D., Bower, P., Lee, V., Middleton, E., Gardner, C., Gately, C. and Rogers, A.** 2008: Cost effectiveness of the Expert Patients Programme (EPP) for patients with chronic conditions. *Journal of Epidemiology and Community Health* 62, 361–67.
- Robinson, D.** 1971: *The process of becoming ill*. London: Routledge and Kegan Paul.
- Rogers, A., Bury, M. and Kennedy, A.** 2008: Rationality, rhetoric and religiosity in health care: the case of the Expert Patients Programme. *International Journal of Health Services* (in press).
- Rogers, A., Kennedy, A., Nelson, E. and Robinson, A.** 2005: Uncovering the limits of patient-centeredness: implementing a self-management trial for chronic illness. *Qualitative Health Research* 15, 224–39.
- Rogers, A. and Nicolaas, G.** 1998: Understanding the patterns and processes of primary care use: a combined quantitative and qualitative approach. *Sociological Research Online* 3.
- Rogers, A. and Pilgrim, D.** 1991: Pulling down churches: accounting for the British mental health users' movement. *Sociology of Health and Illness* 13, 129–48.
- Rogers, A., Popay, J., Williams, G. and Latham, M.** 1997: Health variations and promotion: insights from the qualitative research literature. *Health Education Authority* 80.
- Sanders, C., Rogers, A., Gately, C. and Kennedy, A.** 2008: Planning for end of life care within lay-led chronic illness self-management training: the significance of 'death awareness' and biographical context in participant accounts. *Social Science and Medicine* 66, 982–93.
- Sanders, C. and Rogers, A.** 2007: Theorising inequalities in the experience and management of chronic illness: bringing social networks and social capital back. In Kronenfeld, J., editor, *Research in the sociology of health care*, Volume 25. Bingley: Emerald, 15–42.
- The Boston Women's Health Book Collective.** 2005: *Our bodies, ourselves*. New York: Simon and Schuster.
- Townsend, A., Wyke, S. and Hunt, K.** 2006: Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness. *Chronic Illness* 2, 185–94.
- Tuckett, D., Boulton, M., Olsen, C. and Williams, A.** 1985: *Meetings between experts: an approach to sharing ideas in medical consultations*. London: Tavistock.
- Wadsworth, M., Butterfield, W. and Blaney, R.** 1971: *Health and sickness: the choice of treatment*. London: Tavistock.
- Wanless, D.** 2002: *Securing our future health: taking a long-term view* (Final Report). London: HM Treasury.
- Wilkinson, R.G.** 2001: *Mind the gap: hierarchies, health and human evolution*. Yale University Press.
- Wilson, P.M.** 2001: A policy analysis of the Expert Patient in the United Kingdom: self-care as an expression of pastoral power? *Health and Social Care in the Community* 9, 134–42.