

The UK Expert Patients Program: lessons learned and implications for cancer survivors' self-care support programs

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UK Expert Patients Program: implications for cancer survivor self-care programs

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ABSTRACT

Introduction

Globally, the enablement of self-care is increasingly being recognised as an essential component of chronic disease management. Within the United Kingdom a key self-care policy initiative is the Expert Patients Program. Developed from the Chronic Disease Self-Management Program, this is a six week self-management education program for people with different chronic diseases, facilitated by lay volunteers.

Methods

As an example of a major public health initiative designed to enhance self-management in long-term conditions, this paper draws on evaluations of the EPP and CDSMP and analyses the implications for the development of similar programs for cancer survivors.

Results

There are a number of evaluations of the CDSMP which suggest significant improvement in participants' chronic disease management self-efficacy and some evidence of healthcare utilization reduction. However, whilst the national evaluation of the EPP demonstrated similar improvements in self-efficacy and health status, there was no significant effect on healthcare utilization. Trials of such programs need to be treated with some caution as participants are often not typical of the general population, and as a complex intervention effectiveness is inherently difficult to assess. Qualitative evaluations revealed that the EPP's strength was derived mainly through peer support and learning. Nevertheless, a number of contextual problems were identified including recruitment, clinicians' lack of engagement with the program and inflexible course materials.

Conclusion

Lay-led self-care support programs such as the EPP have a significantly positive effect on self-efficacy which could be of benefit to cancer survivors. However, a number of lessons should be learned from the EPP when developing similar initiatives for cancer survivors.

- **Self-care**
- **Patient education**
- **Chronic disease**
- **Cancer survivorship**
- **Expert patient**

Introduction

The importance of self-care and self-management in chronic disease and oncology is increasingly being recognised as the essential foundation for effective management of long-term conditions (1, 2). Often confused terms with no gold standard definition (3, 4), for the purpose of this paper self-care is defined as an individual's actions focusing on preventative measures in order to gain or maintain a level of health, whereas self-management is focused upon disease management generally guided at some point by a clinician and often involving the individual in making therapeutic adjustments to a treatment regimen (5-7).

Triggered by the increasing global prevalence of long-term conditions(8), there are a number of factors that have placed self-care and self-management at the top of many long-term condition policy agendas around the world. There is recognition that the acute care model with a relatively passive patient is inappropriate in enduring conditions, rather the aim is to have informed, activated patients who work in partnership with their clinician (1). It is also suggested that a fully engaged public who self-care appropriately will reduce the financial costs for a health service (9). From the patient's perspective, it is often argued that self-care is an active, responsible and flexible process that will result in personal development (10) and increased self-esteem (11), with some tentative research indicating a link between autonomy, self-esteem and improved health outcomes (12).

In the United Kingdom (UK) there have been a series of self-care initiatives within the public health arena, aimed at harnessing the potential benefits for individuals and the state as outlined above. These include development of on-line decision support to help patients decide whether they need to consult a doctor (13), and clinician facilitated self-management programs for hard to reach populations, such as those

with serious mental health problems who have concurrent physical long-term conditions (14). However, the flagship public health policy initiative in self-care is the Expert Patients Program (EPP) (15). A lay-led self-care support course for different long-term conditions based on the Chronic Disease Self-Management Program (CDSMP) (16), the EPP had over 3000 completed courses throughout England and Wales by the end of 2006 (17).

The purpose of this paper is to present an overview of the EPP as a major public health initiative aimed at enhancing self-care in long-term conditions. Drawing on the findings of a national evaluation of the EPP (18) and qualitative research (19), the paper will assess the effectiveness of the EPP as a vehicle for enhancing self-care support in long-term conditions and develop an analysis of the implications for the development of similar initiatives for cancer survivors.

An overview of the Expert Patients Program

The roots of the EPP can be traced back to the work of Kate Lorig, whose pioneering research led to the development of the Arthritis Self Management Program (ASMP) in the early 1980's at Stanford University. Early studies showed a rise in health status in participants who completed the program, however no association could be found between this improvement and any changes in behaviour or knowledge (20). Further research indicated that self-efficacy (21); the belief in one's ability to achieve an action, was a key factor in the ASMP's success. In 1990, building on the ASMP's results and in collaboration with Kaiser Permanente, the Chronic Disease Self-Management Program (CDSMP) was developed (16). The CDSMP is based on the assumption that whatever the long-term condition, people need to develop a generic set of skills to self-care successfully (22), and these skills form the content (1, 23).

Positive evaluations of this program and the success of the ASMP which was introduced to the UK by Arthritis Care in the 1980's (24, 25) added impetus to the development of the EPP.

Attracted by evaluative results suggesting it was an intervention that could reduce hospital bed days (23) and that it could be effectively delivered by volunteer lay tutors (26), the UK Department of Health set up a taskforce to develop the EPP. Personally championed by the Chief Medical Officer, the EPP was introduced in 2001 (15) and piloted throughout England and Wales over the next three years (27). The EPP is a six-week small-group intervention attended by people with different chronic conditions, the sessions last 2½ hours. Based on an underpinning of empowerment and inclusion, the chronic condition is self-defined by the participant who self-refers to the program often in response to newspaper advertising. Acting as role models, it is taught by peer instructors from a highly structured manual based on self-efficacy theory. The content is shown in Table I, but central to the course is the setting of weekly goals and action planning. To enhance self-efficacy, participants are encouraged to set goals of their choice that they are reasonably confident about achieving (1). Thus, walking round the block three times a week may be more realistic for many participants than 30 minutes on a gym-based treadmill every day. Success in reaching goals is therefore likely to increase confidence and facilitate the participant in achieving more health-related behaviour changes. Participants are encouraged to keep to their action plan by a weekly feedback time at the beginning of the session and peer support. The course material is supplemented by a participant handbook (28).

It should be noted that the EPP is particularly cost-effective as it is delivered by a volunteer workforce. Via a standardised training day and assessed delivery of two

programs, suitable lay people who have a long-term condition themselves are taught to facilitate the EPP as lay tutors (29). They are provided with a manual and are required to adhere rigidly to the teaching material in it. Lay tutors are expected to deliver at least two courses annually. Each program has between 10-20 participants and ideally two lay tutors facilitate each course. There is regional support for the lay tutors from paid EPP trainers. Costs are also minimised by the use of low-tech teaching aids such as flip charts. Wherever possible the venues for the program are community based, such as a church hall accessible for the disabled, rather than health care premises.

Effectiveness of the chronic disease self-management program

As a precursor to the EPP, evaluations of the CDSMP are of relevance. Lorig *et al's* (23) randomized controlled trial (RCT) comparing the 6 month outcomes of an intervention group (n= 664, attended CDSMP) with a control group (n= 476, waiting list for CDSMP) showed significant improvements for the intervention group in the amount of physical exercise taken each week, increased practice of cognitive symptom management and improved communication with their clinician. The intervention group also demonstrated significant improvement in self-rated health, disability, social/role activities limitation, energy/fatigue, and health distress. However, despite these positive outcomes there was no significant improvement in reported levels of psychological well-being and pain or discomfort. The lack of improvement in psychological well-being somewhat negates improved self-efficacy in other health outcomes, however this may be more related to the lack of change in symptoms which are dependent on functional or behavioural changes rather than self-efficacy. Results indicating healthcare utilization suggested a significant decrease in

the number of hospitalized nights for the intervention group but no statistically significant decrease in patient visits to their physician.

As a follow-up to this trial Lorig *et al* (30) conducted a controlled before-after cohort study involving eligible participants (n= 831) from the earlier RCT. Main outcome measures of health behaviour, self-efficacy, health status and health care utilization were assessed via a self-administered questionnaire at baseline, 6 months, 1 year and 2 years. There were significant increases in intervention group self-efficacy and fewer visits to the physician both at 1 year and 2 years, however there was an increase in disability at year 1. By the end of year 2 there were no significant changes in variables except self-rated health and energy/fatigue but outpatient healthcare service use continued to be significantly reduced. However, it may be unrealistic to expect persistent changes in those affected by chronic illness, rather a slowing down in decline may be the aim for many people. There may also be a need for booster sessions if improvements are to be maintained.

Other studies have demonstrated significant increases in participant self-efficacy within the 6 months following completion of the CDSMP. Farrell *et al's* quasi-experimental pretest-posttest (31) evaluation measured changes in self-care and self-management behaviour, for example the time spent performing physical activities, and behaviours in communicating with health providers such as preparing a list of questions. The participants had a range of chronic diseases and co-morbidities including diabetes, hypertension and arthritis. As in other evaluations, self-efficacy in chronic disease self-management was also measured. Results indicated significant improvement in self-efficacy in managing symptoms, disease and self-management and self-efficacy in health (the confidence the individual has in being able to influence their health status). However, the sample for this study (n=48) was very

small. The CDSMP has been delivered globally and there are a number of evaluations of the adapted program for use within different cultures and languages (32-36).

Dongbo *et al's* (34) RCT of the CDSMP in Shanghai, China, showed a significant improvement in the intervention group's exercise and cognitive symptom management. However, while the sample size was large (treatment group n=430 and control group n=349), it should be noted that recruitment excluded patients for whom problems with compliance could be expected.

Clinical and cost effectiveness of the EPP

The UK Department of Health commissioned an independent evaluation of the pilot phase of the national EPP implementation. A RCT (37) recruited potential EPP participants throughout England during 2003-2005. The participants recruited (n=629) were randomized into an immediate EPP (n=313) or on to a 6 month waiting list control (n=316). In the intervention group, participants who attended 4 or more of the 6 EPP sessions were considered to be course completers. Measures utilised in the trial were validated self-efficacy scales used in previous evaluations of the CDSMP, self-reported healthcare utilization, and health-related quality of life (EuroQol) (18).

Measures were taken at baseline and 6 months and in addition a cost effectiveness analysis was undertaken. Results comparing the 79.2% (n=248) who completed the 6 month follow-up in the intervention group and the 86.4% (n=273) who returned the 6 month follow-up in the control group are shown in table 2. The results indicated a significant increase in self-efficacy of the intervention group, increased energy levels, an overall significant improvement in psychological well-being, reduction in social role limitations and health distress. However, a number of other outcomes such as exercise did not show any significant improvement. In addition, despite significant

improvements in self-reported partnership with clinicians there was no significant reduction in health care utilization. Nevertheless, the cost-effectiveness analysis showed the EPP was likely to be cost effective at conventional levels of decision-makers willingness to pay.

A similarly designed trial of an EPP attended by the Bangladeshi population in East London (38) indicated similarities with the national evaluation such as an increase in self-efficacy, however there were no changes in a wide range of health status measures and health care utilization.

Results from evaluations of programs such as the CDSMP and EPP need to be treated with some caution (26). Such programs are made up of heterogeneous groups who self-identify that they fill the program recruitment criteria and self-volunteer, therefore they may not be typical of the total chronic disease population. Additionally and as indicated by the differences between Rogers *et al's* (37) and Griffiths *et al's* (38) findings it is difficult to generalise between populations. Despite attempts at standardizing the teaching methods and material there is also bound to be some variation in delivery between programs. Finally, as a complex intervention with a multitude of causal complexities it is inherently difficult to assess the effectiveness of such a multifaceted intervention (39). Hence qualitative analyses of participant experience and the contextual environment can do much to expand understanding of how such programs work.

The EPP: an analysis of patient experience and contextual factors

Similar themes emerged from 2 process evaluations conducted during the pilot phase of the EPP (40, 41) that suggested a number of barriers to effective implementation of the initiative (table 3). Reported in depth elsewhere (4, 19), one of the major findings

of Wilson *et al's* study of more than 100 patients with chronic disease and 100 clinicians (physicians, nurses and physiotherapists) was the lack of engagement clinicians had with the EPP. The national evaluation highlighted health professionals' lack of awareness of the program and lack of acceptance of the validity of lay-led self care support training programs, which may be connected to the policy decision excluding health professionals from a discrete role in EPP facilitation and administration. This lack of engagement impacted on the difficulties in recruitment experienced during the pilot phase, and is an on-going issue (42). Whether recruitment was a particular issue for the EPP compared to other self-care support programs is unclear, however, efforts and further research is required in order to increase recruitment. Furthermore, Wilson *et al* (4) suggested that for some clinicians such as nurses there was resistance to the notion of active, self-managing patients who were perceived as a threat, and there is evidence that the term "expert patient" has caused disquiet (43).

These issues were further amplified at an administrative level because the EPP was run discretely and did not follow the pattern of the normal National Health Services (NHS) in England and Wales. NHS services are characterised by physicians' acting as gatekeepers and services being provided separately in primary and hospital based care. Because the EPP pilot was hosted rather than run by primary care organizations it did not fit easily with primary or secondary care. Equally alien was the concept of a workforce made up of volunteers (44) which resulted in time-consuming administrative problems. These included the difficulties of providing cover when tutors (who all had a chronic condition) were unexpectedly off-sick, recruiting enough tutors to run the programs, and maintaining quality control (40). Self-referral to the course was also a new concept when compared with many NHS services and

recruiting enough participants to make a public health impact has been an on-going issue. In the pilot phase recruitment issues were compounded by a lack of communication between many primary care organizations (41). Unsurprisingly, the EPP was more successful in terms of recruitment in organizations that had invested more into course administration, held more awareness days and had clinicians who appeared more interested and supportive of the EPP (45). Nevertheless, recruitment often failed to reach those most in need such as marginalized groups.

The outcome evaluation suggested that self-care behaviours around health care utilization were unaffected by attendance on the EPP. It is suggested that this is linked to recruitment in the pilot phase often resulting in programs where participants already had established self-care practices (37) and expert patient characteristics such as partnership working with clinicians (19). Nevertheless, there was a marked increase in reported levels of self-efficacy and qualitative analysis indicates that much of this confidence is gained through peer learning and support but can be detrimentally affected by negative participants in the group (19). Whilst fellow participants provided much of this support, the volunteer tutors were seen as central to the program success (19, 37), with facilitation style, role modelling skills and personality all identified as key factors.

However, albeit programs may be facilitated by a highly effective tutor, the process evaluations revealed a number of issues around course content and delivery. As part of quality assurance tutors are expected to stick rigidly to a teaching manual, however this rigidity often resulted in material not being presented in a way adapted to the group's particular needs. In addition, the course content was found to be too crammed and rushed often resulting in meaningful discussion being prematurely stopped (19, 37). Some of the course content was also found problematic such as Living Wills

(advanced directives that an individual wishes to be operationalised when they are incapacitated), which both participants and tutors often found difficult to negotiate. However, whilst Rogers *et al* (35) suggested that for some participants the generic nature of the course was problematic, Wilson *et al* (19) identified the generic material a strength with participants finding sharing information about self-care strategies in a number of conditions helpful.

As the evaluations were conducted during the pilot phase of the EPP, neither identified whether as a public health initiative the EPP was impacting on positive change in the community. However, Wilson *et al* (17) describe early indications that the EPP may be triggering a health consumer movement, with course participants continuing to meet regularly after course completion and actively trying to influence service provision.

Overall, evaluations of the EPP suggest that it is a cost-effective useful tool within a range of self-care initiatives. There are lessons to be learned from the evaluations and the implications of these will now be discussed in relation to similar potential initiatives with cancer survivors.

Lay-led self-care support programs – a suitable model for cancer survivors?

Until recently the majority of work towards supporting the self-care needs of cancer patients has focused on issues surrounding the treatment phase such as decision-making (46), managing the side-effects of the treatment (47, 48), or on the early stages of the cancer journey (49), and specific symptom control (50). Cancer survivorship is increasingly being recognised as a major public health issue with survivors facing many similar health, psychological (51) and socioeconomic challenges as those affected by chronic disease (52, 53). However, apart from some

notable exceptions (54) there has been comparatively little work on developing and evaluating self-care support programs for cancer survivors. A systematic review of the literature surrounding the support of self-management in people affected by cancer reported a lack of a coherent body of literature on the topic, with the few studies included often lacking a theoretical base and methodologically weak (55).

However, recently there have been emerging examples of self-care support programs for cancer survivors. In the United States, the Taking CHARGE program is aimed at the largest group of cancer survivors; women with breast cancer. Based on social cognitive theory (21), the program comprises of four, two weekly interventions facilitated by a nurse or health educator. The interventions are made up of two small group sessions and two, one-to-one telephone sessions with the nurse/health educator. The content focuses on managing the psychosocial problems following the treatment phase, managing specific symptoms such as fatigue, and coping with social roles. A process evaluation (56) of an unpublished RCT of 49 women who either undertook the program (n=25) or had usual care (n=24) indicated that self-efficacy was increased. Suggestions for improvement included more group sessions as the peer support was highly appreciated.

The value of peer support for cancer patients is recognised (49), but programs such as the CDSMP and EPP take peer support further. Having a peer as group facilitator is a significant difference from many current self-care programs in oncology. In the UK a cancer charity has implemented the Living with Cancer course (57). Based on the EPP it is a 6 week, peer facilitated self-care support that aims to help participants identify ways of managing symptoms and side effects of treatment, including relaxation techniques and visualisation exercises. Similarly, in Australia the CDSMP has been adapted, piloted and evaluated for cancer survivors (58). Participants (n= 29 cancer

survivors and n=11 carers) who attended one of two “Staying Healthy after Cancer” courses were compared to cancer survivors who attended a generic CDSMP (n=13). The qualitative evaluation utilising telephone interviews 4-6 weeks after each program suggested a strong preference by cancer survivors for the cancer specific rather than generic program, with many respondents citing the need for specific detail relating to cancer. Interestingly, carers preferred the generic program with the researchers linking this to a desire from carers for the participants to be able to see beyond the cancer. This finding regarding the strength of the generic version enabling people to put their own situation in context echoes evaluations of the EPP (41). Similarly, a desire from the cancer survivors for discussion time to be increased and for the content to be less rushed possibly by lengthening the program is resonant of the EPP evaluations. Whilst the evaluation of the “Staying Healthy after Cancer” program recommends cancer specific CDSMPs with extra modules focusing on specific issues for cancer survivors such as recurrence, it should be noted that the evaluation is methodologically weak (56). The sample is small and completers were identified as those who had completed only one session, it is not clear how many respondents completed the whole program. Additionally the effect of having the carer present on the program is not explored. Having carers participate in the EPP has been problematic and issues around tension between the needs of the carer and those cared for have been observed. Within England there is the imminent development of the Expert Carer’s Program (ECP) responding to the distinct needs of carers (59). The differences between the EPP and ECP have been described as the former focusing on caring for oneself and the latter being having the additional content of caring for someone else too (60). Nevertheless, the Australian pilot does indicate a significant

increase in a sense of control for participants, enabling a change of perception from being a patient to being a survivor.

Conclusion

Whilst there is little doubt that lay-led self-care support programs have a significantly positive effect on self-efficacy as evidenced by the EPP, there is still the need for rigorous research to strengthen the evidence base. Currently, the evidence suggests that for longer term outcomes targeting those most likely to benefit from such programs would be of benefit. The EPP and other similar courses have had a tendency to attract well-educated participants who often already effectively self-care and the challenge will be to attract those most in need of these programs. In addition, providing post program follow-up sessions may be of benefit in the longer term, and the current evidence indicates that programs should be part of a range of self-care initiatives. However, outcomes for this type of initiative should not be solely determined by professionals or be based exclusively on societal needs such as a reduction in health care costs. In reviewing the research surrounding the EPP initiative it appears that there is less of a focus on the outcomes that participants themselves want to gain from such programs. Reliance on empirical and societal defined outcomes often hides success in terms of participant defined outcomes. In addition, the difficulties in evidencing the empirical effectiveness of complex programs may contribute to the lack of value and engagement placed on such models by clinicians.

For these programs to be successfully implemented there needs to be a corresponding effort to engage clinicians and health administrators with the underpinning philosophy and benefits. This will involve mechanisms that enable recognition of lay expertise in

self-care. The experience of the EPP suggests that simply labelling a program “Expert Patient” may be detrimental to this by appearing to directly equate patient expertise with professional expertise. Hence, the title of a program should not be underestimated as an important factor in clinician engagement. Equally, alongside such initiatives there should be concurrent professional education at both under and post graduate levels (4, 19) and awareness raising. Benefits of new ways of working with self-caring and self-managing managing patients should be explicated within the training and be underpinned by principles of concordance rather than compliance (61).

Moreover, the course content must respond flexibly to the group’s needs and, whilst peer tutor facilitation is highly valued, further thought may be needed about preparing them in having the skills to flexibly adapt course material. Finally, health care providers need to acknowledge that bringing people together to share experiences may empower them to develop as a health consumer movement who may actively wish to address shortfalls in service provision. For people living with a long-term condition this can only be a positive outcome.

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Expert Patients Program Content

Week	Course content
1	Action planning, relaxation, better breathing
2	Action planning, anger, fear and frustration, fitness and exercise
3	Action planning, relaxation, fitness and exercise, fatigue
4	Action planning, relaxation, nutrition, living wills, communication
5	Action planning, relaxation, medications, making treatment decisions, depression
6	Action planning, relaxation, communicating and working with the health care team, future plans

Table 1

EPP outcome evaluation: Outcomes at 6 month follow-up

Outcome	Unadjusted intervention scores Mean (SD; n)	Unadjusted control scores Mean (SD; n)	Adjusted difference (95% a)*	p Value	Effect size **
Primary outcomes					
Self-efficacy	60.3 (19.6;237)	52.1 (21.2;267)	8.9 (6.2 to 11.5)	0.000	0.44
Energy	37.7 (21.4;247)	35.0 (20.8;273)	3.7 (1.2 to 6.3)	0.004	0.18
Health care visits	6.29 (7.4;248)	6.77 (7.5;273)	-0.20 (-1.35 to 0.95)	0.732	0.03
Secondary outcomes					
General Health	2.64 (0.9;247)	2.75 (0.9;273)	-0.10 (-0.22 to 0.01)	0.083	0.11
Social role limitations	45.4 (29.9;248)	51.4 (30.4;273)	-5.6 (-9.2 to -2.0)	0.002	0.19
Pain	62.6 (26;237)	64.8 (24.5;267)	-2.4 (-5.4 to 0.7)	0.129	0.10
Psychological well-being	64.8 (20.5;247)	61.2 (20.9;272)	5.1 (2.7 to 7.6)	0.000	0.25
Health distress	41.3 (26.2;247)	46.8 (25.8;272)	-5.1 (-8.4 to -1.7)	0.003	0.20
Exercise	160.2 (132.6;247)	152.6 (155;273)	18.8 (0.3 to 37.3)	0.047	0.13
Partnership with clinicians***	56.5 (23.5;236)	62.6 (23;267)	-5.7 (-9.5 to -1.9)	0.003	0.25
Diet	2.3 (0.6;234)	2.3 (0.7;266)	0.08 (-0.02 to 0.17)	0.126	0.12
Complementary products	1.6 (0.6;234)	1.6 (0.7;266)	-0.03 (-0.12 to 0.07)	0.562	-0.05
Relaxation	2.1 (0.5;226)	2.0 (0.6;257)	0.11 (0.02 to 0.21)	0.018	0.20
Information seeking	2.3 (0.7;229)	2.2 (0.7;261)	0.09 (-0.02 to 0.19)	0.096	0.13
<p>* Values adjusted for baseline outcome values and all minimisation variables as covariates (general health, main condition, gender, age, ethnicity and accommodation status)</p> <p>** Effect size based on adjusted difference in means divided by the pooled standard deviation. Positive effect size represents favourable outcome for intervention.</p> <p>*** Low scores indicate favourable outcome</p>					

Table 2

Source: Kennedy *et al* (2007) 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. *J. Epidemiology & Community Health* 61, 254-261

Barriers to effective implementation of the EPP

Engagement of clinicians	<ul style="list-style-type: none"> • Lack of awareness • Limited acceptance of validity & usefulness of self-care support programs • Resistance to the concept of “expert” patient
Recruitment	<ul style="list-style-type: none"> • Clinicians unlikely to suggest EPP to patients • Public lack of familiarity with self-referral
Targeting most in need groups	<ul style="list-style-type: none"> • Advertising and networking unlikely to reach those with poor health literacy • Lack of clinician engagement resulted in those most in need of developing self-care skills unlikely to be recommended EPP • Lack of programs adapted for culturally diverse groups
Volunteer workforce	<ul style="list-style-type: none"> • Quality control mechanisms • The need for support • Sick leave cover • Problems in recruiting lay tutors both in numbers and suitability

Table 3