

**The Expert Patients Programme: A paradox of patient empowerment and
medical dominance**

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ABSTRACT

Self-care is seen as a key element in managing resource demand in chronic disease and is also perceived as an empowering right for patients. The Chronic Disease Self-Management Programme developed in the United States has been adopted in a number of countries and in the United Kingdom has been adapted as the Expert Patients Programme. However, despite its potential as a lay-led empowering initiative, the Expert Patients Programme has been criticised as perpetuating the medical model and failing to reach those in most need.

This paper revisits a critique of the Expert Patients Programme (Wilson 2001), and drawing upon a qualitative study seeks to explore whether the Expert Patients Programme enables empowerment or replicates traditional patterns of the patient-professional relationship. A grounded theory approach was adopted utilising focus groups, in-depth interviews and participant observation. Data was analysed via the constant comparative method and the development of codes and categories. Conducted in the relatively affluent area of the south east of England, respectively over one hundred adults affected by a range of physical long-term conditions and health professionals involved in chronic disease management agreed to participate in the study. Drawing on the data from individuals with a chronic illness who were knowledgeable, active and informed, the study revealed a number of characteristics common to expert patients that were linked to a systematic, proactive and organized approach to self-management, a clear communication style and the ability to compartmentalise emotion. The study included participant observation of an Expert Patients Programme and a professional-led self-management course. The

paradoxical nature of the Expert Patients Programme was revealed, for whilst there was evidence that it reinforced the medical paradigm, there was a concurrent acknowledgement and support for the subjective experience of living with a long-term condition. Furthermore, whilst the policy emphasis has been on individual empowerment within the Expert Patients Programme, there is some evidence that it may be triggering a health consumer movement.

Key words

- Chronic disease
- Self-care
- Expert patient
- Patient participation
- Patient education

Introduction

Self-care in chronic disease is seen as a significant element in managing resource demand (Bodenheimer *et al.*, 2002) and is also regarded as an empowering right for patients (European Parkinson's Disease Society, 2003; Salter, 2004). Within the United States (US) pioneering work has explored the most effective way to enable people to be able to self-manage their long term condition effectively with the development of the Chronic Disease Self-Management Programme (CDSMP) a key contributor to the body of knowledge. The CDSMP is a six week, lay-led, self-management skills training course for generic long-term physical conditions with evaluations suggesting improved outcomes and some cost reductions for chronic care (Lorig *et al.*, 2001; Lorig *et al.*, 1999). The CDSMP has been evangelised globally with a number of governments adopting the programme as part of a long-term conditions strategy, examples include the Sharing Health Care Initiative (Australian Government Department of Health and Ageing, 1999), Diabetes Self-Management Programme in British Columbia, Canada (McGowan, 2004) and the Expert Patients Programme (EPP) in the United Kingdom (UK) (Department of Health, 2001). Despite a number of positive outcome evaluations of courses based on the CDSMP (Barlow *et al.*, 1998a; Dongbo *et al.*, 2003; Farrell *et al.*, 2004; Schreurs *et al.*, 2003) the model is not without critics. There are concerns that evaluations have tended to ignore those participants who have dropped out of the programme (Bury & Pink, 2005) and that the courses have failed to recruit those most in need (Anderson, 1996). This paper revisits a critique developed as the EPP commenced a pilot phase within the UK (Wilson, 2001) which suggested that the EPP was unlikely to be empowering, not least because of the maintenance of medical power extending into the realm of self-care. Within the UK and elsewhere, the discourse of empowerment is most

commonly articulated in patient participation and public involvement initiatives (Baggott, 2004) such as the EPP. However, a tension may exist between empowerment and the medical profession if participation and involvement is operationalised purely at a tokenistic level (Guadagnoli & Ward, 1998; Pattison, 2001; White *et al.*, 2004), and hides a continuing professional agenda (Daykin *et al.*, 2004) focusing on compliance (Henwood *et al.*, 2003; Wilson, 2001).

Drawing on a grounded theory study which explored the concept of the expert patient and the EPP as a potential mechanism for facilitating patient expertise (Wilson *et al.*, 2005), this paper seeks to explore whether the EPP enables empowerment or replicates traditional patterns of patient-professional relationships. Findings from the study regarding health professionals' responses to expert patients have been reported elsewhere (Wilson *et al.*, 2006). The focus of this paper is firstly to present the characteristics of expert patients and secondly the experience of self-management programmes. The paper will explore whether the EPP reinforces the characteristics of the expert patient within a medical paradigm, or as espoused serves to enable patients to take control and thus be empowered.

Background

The UK concept of the expert patient derives from the assumption that individuals affected by a chronic illness over a number of years are likely to develop expertise in managing their condition (Department of Health, 2001). It has been suggested that this expertise is likely to be different in nature to the knowledge a health professional has acquired with lay expertise located in the individual experience of the condition and development of discrete strategies (Koch *et al.*, 2004).

Much work has been undertaken on the development of self-management skills within specific conditions (Goudswaard *et al.*, 2004; Lahdensuo *et al.*, 1996; Riemsa *et al.*,

2002) resulting in a number of patient education programmes. Usually led by a health professional these programmes aim to improve compliance with condition specific therapies. However, there is evidence to suggest that this type of approach does not necessarily lead to improved health outcomes unless individuals are empowered to take over aspects of self-management that are the traditional province of health professionals, such as therapeutic adjustments to medication (Gibson *et al.*, 2002).

The idea of empowerment as a vital element in patient self-management is the cornerstone of CDSMP based courses. Drawing upon self-efficacy theory (Bandura, 1986; Bandura, 1995) there is an assumption that if individuals feel confident that they can control their condition rather than the reverse, then they will be able to do so (Williams & Bond, 2002). Arguably the most empowering aspect of CDSMP based courses is that it is not facilitated by a health professional but by a lay volunteer who has a long term condition themselves (Kennedy *et al.*, 2005b). Thus the material is supplemented by the coaching role of an expert patient who has had some training in running the programme (Department of Health, 2005). However, despite the involvement of lay tutors, Wilson's (2001) critique suggested that there were a number of underlying power issues within the EPP that had the potential to inhibit any sense of empowerment. Using Galbraith's (1984) three rules of power it was argued that power may be withheld from EPP participants in three ways. First, participants may feel obliged to undertake the EPP because of perceived or actual coercion from health professionals. Second, participants submit to the self-management practices taught because the benefit, such as the social network an EPP may create, brings an affirmative award. Lastly and indicative of the current UK government's dualistic approach to citizens' rights and responsibilities (Wilson, 2001), the EPP exercises conditioned power by operating in an environment where self-management is not only

seen as a right but as a responsibility (Gilbert, 2005). Wilson's (2001) concerns have been echoed by other commentators who have also identified the EPP's potentiality for reinforcing the medical paradigm rather than being a vehicle for empowerment (Davidson, 2005; Fox *et al.*, 2005). Equally, it has been questioned whether all patients want to participate in self-management (Sanders & Skevington, 2003) and if it is a viable option for all, especially when health literacy levels are low (Gazmararian *et al.*, 2003; Pickard *et al.*, 2002).

Methodology

As the notion of the expert patient is a relatively new and under researched phenomenon a grounded theory approach was adopted (McCann & Clark, 2003; Strauss & Corbin, 1990). Whilst the study included over one hundred health professional participants (doctors, nurses and physiotherapists) and over thirty patients attending chronic disease clinics (Wilson *et al.*, 2006), the data captured through a variety of methods from the remaining patient sample is specifically drawn upon to illuminate this paper. Through purposeful and theoretical sampling these included people who actively self-managed their condition but had not necessarily attended a self-management course, and a number of people who were less active in self-management. Active self-managers or expert patients were first identified by the individual's own definition. Second, by using the description of an expert patient as someone who actively offers treatment suggestions, knows what to expect from treatments and when to access professional help (Jones, 2003), the identification of expert patients was further verified by subsequent researcher analysis of the data.

Sampling & data collection

In order to be illuminative and in common with other social research a mix of methods were adopted (Moran-Ellis *et al.*, 2006). Two focus groups (Morgan, 1997) with adults respectively affected by cardiac disease (n=7), diabetes (n=6) were purposefully sampled (Cutcliffe, 2000). As themes began to emerge regarding the effect of the condition on both individual and partner, a third group of individuals and spouses affected by Parkinson's disease (n=9) was theoretically sampled (Strauss & Corbin, 1990). Within the groups participant experience of a professional-led self-management course ranging from forty percent of the group (diabetes) to one hundred percent (cardiac). None of the participants had accessed an EPP but all actively self-managed their condition. Participants had been diagnosed between five and twenty five years and were all members of a support group. A series of prompt questions was used to trigger discussion on participants' experience of their condition and their development of self-management skills. The discussion was audio-taped and transcribed.

Via purposeful sampling in-depth interviews were carried out with eleven individuals affected by a range of long-term physical conditions such as Multiple Sclerosis (MS) and Rheumatoid Arthritis. Of these five had attended an EPP within the last six months, five were on the waiting list to attend an EPP and one had attended a professional-led self-management course. A further eight individuals were theoretically sampled to confirm the theoretical relevance of the emerging themes (Strauss and Corbin, 1990), all were recruited via different support groups. As EPP lay tutors were identified as emblematic cases (Gobo, 2004), two tutors were also interviewed, one had facilitated four EPPs, the other had been involved in two. An interview guide was used to prompt the semi-structured interviews (Kvale, 1996) with triggering questions used to explore respondents' experiences of their condition, self-

management strategies, and when appropriate the experience of participating in or facilitation of the EPP. Interviews were audio-taped and transcribed.

The third method utilised was observation (Jorgensen, 1989). To provide a contrasting model of self-management programme and to ensure multiple data sources an eight week professional-led Back Fitness Course (BFC) and an EPP were observed. The former comprised of weekly two hour sessions with the first hour being exercise based and led by a fitness trainer. The second hour was facilitated by a psychologist with a group work approach exploring a range of topics such as pain and stress management (figure 1). Ten participants were registered to attend the course having been referred by a medical consultant or specialist physiotherapist. All participants were affected by chronic back pain and their ages ranged from thirty to fifty eight years old. The six week EPP followed the standardised content (figure 1) and had thirteen participants with ages ranging from forty four to seventy nine years old. The participants were affected by a number of conditions including arthritis, diabetes, epilepsy and chronic depression, from the start of the course four participants could describe established self-management skills. All had self-referred to the programme in response to advertisements in Health Centres or the local press, three had been part of the interview sample whilst on a waiting list for the EPP. The EPP was facilitated by two lay tutors, one affected by MS and the other affected by endometriosis, the former was interviewed prior to delivery of this EPP, the latter was interviewed three weeks after the observation was completed.

The researcher carrying out the observation (PW) undertook a number of roles (Waddington, 1994). Within the BFC the exercise element was observed from a discrete distance with contemporaneous detailed field notes written. However, it was felt that this would be too intrusive during the small group work and so the researcher

took on an observer as participant role with audio-taped field notes recorded as soon as possible after the session. Despite approval from the appropriate Ethics Committee for all the data collection processes, access to the EPP proved a little more difficult (Gerson & Horowitz, 2002) with concerns that having a researcher present could compromise the running of the course. These anxieties were addressed by PW taking on a participant observer role and using her own experiences of living with a long term condition to fully engage with the EPP.

Ethical issues

Whilst the participant observer role provided enormous possibilities for rich data (Savage, 1995) it was also acknowledged within the research team that there were potential issues ethically (Sanchez-Jankowski, 2002). This was addressed by obtaining informed consent from the participants each week and reminding them of PWs research role (Moore & Savage, 2002).

Analysis

The data generated from the different methods was given equal weight and following an initial analysis was integrated as a whole (Moran-Ellis *et al.*, 2006) with further interrogation using the constant comparative method (Glaser & Strauss, 1967). All data was manually open coded with conceptual and axial coding developing from this (Donovan, 1995). This process continued until data saturation was achieved and core categories emerged (Strauss & Corbin, 1990).

Rigour

Rigour was enhanced in a number of ways. Field notes for the EPP observation took the form of an audio diary utilising a reflective framework and recorded immediately after each session. As with all the data, the themes from the audio diary were discussed within the research team to aid inter-rater reliability (Pope *et al.*, 2000). In

addition an individual experienced in qualitative research but also attending an EPP elsewhere as a participant agreed to record a personal reflective diary. Post analysis of the data a reflective dialogue was conducted with this researcher which acted as a constructive interrogation and confirmed congruence between the two sets of experiences. In addition the findings were presented to participants for member checking of data interpretation (Lincoln & Guba, 1985). Finally, the use of mixed methods provided a model of triangulation with increased validity (Moran-Ellis *et al.*, 2006).

Findings

By presenting a number of the broad themes that emerged from the analysis, the characteristics of expert patients and how and if these are enhanced by self-management programmes are explored. This exploration is continued by considering how these characteristics are paradoxically shaped within both the empowerment and medical paradigm.

Being an expert patient

Analysis of the data derived from expert patients revealed a number of common discourses they adhered to.

Systematic, proactive and organized

The majority of expert patients described themselves as systematically organized. This was in relation not only to self-management of their condition such as maintaining a drug regimen, but also in the work involved in minimising the impact of the condition on their lifestyle. Many kept self-initiated diaries or information folders regarding test results and treatments and were able to give very precise medical histories. Commonly expert patients utilised current or past occupational

skills in their role as expert patient. For example, one expert patient was a retired project manager and approached his and his wife's condition in a similar way:

H (wife) wasn't feeling well on a Sunday, saw a GP on first thing Monday morning, was at the (hospital) to have the ultrasound and was diagnosed on the Wednesday, so I got all the information on Non-Hodgkin's Lymphoma by Friday and I sorted out a MacMillan nurse by Friday and saw the Oncologist on the Tuesday. Possibly my project management skills came to the fore" ...

Interview M6

Another expert patient used her occupational skills of teaching not only in the way she organised her condition but also as a proto-professional expert patient:

"I did do a talk in July to the two consultants, a couple of physiotherapists and occupational therapist... they said I was inspirational...but I just did it as though it was a lesson."

Interview F11

Proactive problem-solving skills appeared key in the journey towards being an expert patient. This journey was often started by an active and systematic seeking of information, with the most helpful source being identified as voluntary organizations such as the MS Society. The Internet whilst widely used was perceived as a source that needed to be carefully managed either to prevent overload or misinformation:

there's the dreaded internet, find a word you didn't understand and search for that word, and it's absolutely fatal because ...I convinced myself a couple of weeks ago that I was getting massive heart failure but took 2 paracetamol (acetaminophen) and felt better!

Heart Focus group

Whilst the Internet was mainly accessed for general information about the condition it was also used by some to check on professionals' suggestions:

"...he (GP) wanted to give me Seroxat (paroxetine). I was thinking about taking it because he said it would do something for a few months and then we looked it up on the Internet and I decided no."

Interview F16

The varying use of the Internet reflects findings in other studies (Hardey, 1999; Kivits, 2006; Rogers & Mead, 2004). Gathering information was also part of what many expert patients regarded as a crucial event; preparing for and attending out-patient appointments with the consultant:

I think a lot of the stress is around appointments, making an appointment, getting one, and how precious it is when you get there.

Parkinson's Disease Focus Group

The preparation involved writing aide memoirs, researching alternative treatments in order to enter an informed discussion with the consultant, and where possible ensuring continuity with the same consultant.

"...we are private... because in the NHS you never, ever see the same doctor..."

Parkinson's Disease Focus Group

However, perhaps one of the clearest indicators of an expert patient during the consultation was their communication style and relationship with the clinician.

Doctor-patient relationship: mutual respect

Expert patients described their communication with doctors in terms of being clear and succinct with many reasoning that otherwise consultations may result in going:

“...on a tangent or you talk about minutia...You really want a good picture as well”

Interview M6

This would involve being very precise in what they wanted to gain from the consultation:

“...when I wasn't diagnosed, I think after that I decided I was gonna be assertive and each time I had an appointment with someone, I would have written it all down, exactly what I wanted to know.”

Interview Lay Tutor 2

It was also seen as contributing to the maintenance of mutual respect:

“... he's (GP) respectful of our views and we're respectful of his.”

Interview F6

Mutual respect was often indicative of the nature of the relationship between expert patient and doctor and had generally been built up over time. This relationship was highly valued by expert patients who would make effort to maintain it:

“...I'll always double check “I am seeing him aren't I?” ‘cos I don't wanna see one of the registrars again ... you can ask what you want and he'll explain things to you, even to the extent I'll say “Can I try this?” or “Do you think I should do something in a certain way?” and he'll say “Well, you know, it's your, your condition, you're in charge of it, what do you wanna do?”

Interview F5

As indicated in the above quote this relationship enabled a sense of control for the expert patient. However, if it was perceived that they were not receiving the necessary

treatment or support this style was often adapted to a more challenging one in order to fight for their case, often entailing much effort:

... when you have got a long-term illness, you know energy isn't one of the things that you have and it's mental energy as well. You know writing letters and making phone calls but it's, it's something you have to prioritise...

Interview F15

This labour of being an expert patient not only pervaded physical and communication aspects, but also the management of emotions.

Compartmentalising emotion

Chronic illness brings a mixture of emotional responses for the individual and family that persist over the course of the disease (Bury, 2001) including fear, anxiety, a sense of loss and anger. Having a long-term condition often effects emotional capacity for coping (Mayor, 2006), and all participants acknowledged the impact of the emotional consequences of living with a long term condition. Frustration was frequently cited particularly when participants had not received a firm diagnosis or felt their symptoms were not validated by professionals. The effect of these emotions was commonly depression or a release, often by crying, within patient-professional consultations. However, as reported in more depth elsewhere (Wilson *et al.*, 2006) participants rarely found doctors responding appropriately to these feelings:

“...I did cry at him (consultant) last week and he definitely didn't like that at all, and I thought 'You must get people crying in here all the time'”

Interview F17

Many expert patients described how over time they learned not to discuss their emotional needs within the medical consultation but kept to strict biomedical boundaries, thus compartmentalising emotion away from the medical encounter:

“I’m not a fawning sort of person, with courtesy you tell them what you want to hear and I think basically the medics want some ground rules established, want the boundaries...”

Interview M6

Expert patients utilised a number of strategies to manage and contain their emotional responses. Whilst many admitted some concern about what the future may hold they were also able to articulate a positive vision for the future:

...if it’s not better tomorrow well the next day it may be better tomorrow. You just keep doing each day, you know as it comes along.

Interview F2

This positive perspective appeared linked to a moral dimension with many patients describing a stoical approach where one had to value what you had and just get on with life:

One of them things isn’t it? I’ve always been a believer there’s always somebody round the corner worse off than yourself...

Interview M1

Keeping busy was another strategy and was strongly linked to a moral dimension with expert patients often describing altruistic motives for their behaviours. Their activities included evangelising about their condition to benefit others or helping condition specific campaigns:

“...if I can promote it (arthritis) somehow then I will. Until someone famous gets it or someone that is a figure in society does something for it, it’s not gonna get the recognition it should have really”

Interview F11

This ethic of citizenship was apparent in most expert patients with each actively involved in activities such as voluntary work or being part of Statutory Organizations’ public involvement activities. In the case of the lay tutors this ethic was funnelled into their unpaid work of facilitating the EPP.

Self-management programmes; outcomes, delivery & discourse

The analysis of observation and interview data revealed specific areas that illuminated differences and similarities between the EPP and BFC.

Programme outcomes

The weekly goal planning used in both the EPP and BFC encouraged participants to set themselves achievable goals for the week, with considerable time being spent in the EPP regarding participants’ success with their action plans. The aim of the EPP was described by one participant (Ella) as

...making self-care a habit

Observation EPP Field Notes week 5

Ella had realised that her daily routine had changed, for example she was now walking to the newsagent rather than driving to buy the newspaper. Similarly success of the BFC was seen by organizers in terms of the number of participants who took gymnasium membership and continued with regular exercise after course completion. However, the specific outcomes of the two courses varied considerably. Participants

on the BFC developed knowledge about back pain and learnt specific practical strategies to alleviate it, with the input of the Fitness trainer seen as the main strength of the programme.

At the end of the gym session there were rueful comments and smiles between participants and cheerful goodbyes to Sam (trainer). Chris comments "I know I've done something when I've come here!"

Observation BFC Field Notes week 4

Whilst the EPP did develop some practical strategies, particularly relaxation techniques, outcomes were more of a psychosocial nature when compared with the BFC. The reduction of a sense of stigma was identified by many as an outcome of the EPP and integral to this was validation of their illness experience:

...I think knowing that my fatigue wasn't laziness

Interview F13

For many EPP participants reduced isolation and sharing of problems was the main outcome:

...friends that I've met from the Expert Patients Programme, we still meet up and we chat about different things and what helps...

Interview M4

However this continuing support was often negated if had not been actively promoted by the programme organisers:

...what are we going to do after? ... I think we'd been sort of left out on a limb

Interview F3

Ultimately the EPP had the potential to inspire people and spur them on to further action such as information seeking or joining a support group. The findings also suggested that many participants increased their sense of control over their condition:

Ethel reports to the group with great delight that she has sorted the cupboards out in her house, more than achieving her action plan.

Ethel suffers from chronic depression and has frequently told the group how the state of her house gets her down.

Observation EPP Field Notes week 4

...you feel completely lost with what you're supposed to do and suddenly you're in this room (EPP venue) and you start feeling confident that yeh, it's up to me and I can make this decision....

Interview Lay Tutor 2

Content and delivery

Because of the range of topics covered in the EPP, participants described how it felt too rushed:

It was very very squashed together and a lot of the more elderly people, I should imagine, had trouble taking it in

Interview M4

A lack of depth often made the EPP content feel superficial:

The bulk of the session was on depression.... Whilst the differences between feeling low and depression were acknowledged it was dealt with at a superficial level ... Ethel and Richard who have chronic depression tried to reinforce the difference but the response from others was that it was all about turning your life around.

However, the rigid time limits imposed by the EPP format on each topic appeared to reinforce a sense of having to get one's point over in an efficient manner. Although the material presented on the BFC had greater depth this was not necessarily facilitative of lay understanding:

In depth information given on pain and gate theory but the level and depth of knowledge did not appear to make any sense to the group, one person commenting "do we really need to know this?" There was minimal participation from the group apart from Joyce who is a nurse and at times it felt like a one way physiology lecture between her and the facilitator.

Expert patient discourse

Only the EPP actively encouraged other strategies congruent with the systematic discourse of the expert patient, in particular the use of aide memoirs and preparing for medical consultations was actively discussed, with the Prepare, Ask, Repeat, Take action (P.A.R.T model) (NHS Expert Patients Programme, 2002) modelled by the lay tutors. When the group discussion turned to dealing with perceptions of the difficult doctor participants were encouraged to examine their communication skills emphasising the assertive "I" message, rather than communicating in a way that might give a message of the individual blaming the professional. However, whilst some reported improvement in their confidence when dealing with doctors this was tempered by a perceived lack of change in the way professionals responded to them.

...well I went back to my G.P. and I did say how helpful I thought it (EPP) had been and I photocopied various bits which I'd given this particular doctor, but when I've seen her since she's never commented on it...

Interview F3

Many participants reported doctors devaluing through negation or sidelining the new found “expertise” of the patient.

Whilst the BFC did not deal with communication, informal talk about participants’ experiences with health professionals was common:

While we were waiting for Sam to arrive many of the participants were sharing “physiotherapy stories”; what had happened to them that week and what they perceived as the shortfalls of the physiotherapist, and an overriding sense of frustration that they were not being listened to...

Observation BFC Field Notes week 6

The strength of a generic course

Being able to share experiences of back pain on a condition specific course was important for the BFC participants

There was great excitement this week from Stella because she had been told what was wrong with her. The group gathered around and there seemed a mutual celebration that someone had received a diagnosis. Stella says “at least I know it wasn’t just in my head!”

Observation BFC Field Notes week 4

In contrast the generic nature of the EPP had the potential to create a competitive culture of whose condition was “*worse*”. However, the majority of EPP participants felt that the generic nature could be a strength through sharing common experiences irrespective of the condition and learning about other health issues:

*...a lot of different age ranges, different medical conditions, different walks of life but we all got on well because we're all in the same boat.
We seemed to just click*

Interview M4

Despite the range of conditions the majority of participants shared similar negative consequences of the illness:

We were asked to say the three worse things about how our condition affects us. By far the most common ones stated were frustration and fatigue...

Observation EPP Field Notes week 1

For a number of participants the EPP inspired them to become more informed about their condition:

At tea break Jane said “I've found out a lot more about my disease and the programme has been an influence on that cos there's the resource table and even though I've not put anything on the table it's made me think I should know a little more about my condition...”

Observation EPP Field Notes week 5

Overall, EPP participants felt engaged and enthusiastic about the programme, often attributing the success to the style and attributes of the lay tutors:

The last session and everyone was asked to evaluate the course. Alf states the best thing was the tutors “ ...at last we weren’t being talked at... at last someone who really knew what it was all about was there”

Observation EPP Field Notes week 6

The “problem” participant

There were a small minority of participants who responded negatively to the exercises and suggestions. These latter participants appeared to have a direct impact on programme outcomes, particularly in the EPP. Their negativity regarding the possibility of improving their situation tended to pervade the group and denigrate any potential feel-good factor.

Celia suffers from undiagnosed back pain and speaks about her frustration with doctors...Last week her action plan was to find her Yoga books. She had gone on to do some exercises but reported that this had left her in terrible pain. She was very angry and continued to frown at anything the tutors suggested...”it’s hopeless, what was the point in finding the books, if I try anything I’m doubled up in pain...”

Observation EPP Field Notes week 2

Celia and two other participants had sporadic attendance and their increasing negativity contrasted and challenged other participants’ evolving self-efficacy. These people caused problems for the lay tutors and were their heart sink participants:

The person that doesn’t seem to want to be there, doesn’t see the good in what everyone else is saying and then tries to pick up the negative things. They will never say “Oh yeh, I hadn’t thought of that, I’ll try that”. It’s always “That won’t possibly work”. .

Interview T2

Discussion

As described above, Celia as an example of a “difficult” EPP participant resonated with descriptions of doctors’ heart sink patients reported widely elsewhere, for example someone with long term medically unexplained symptoms (Salmon & Hall, 2003; Steinmetz & Tabenkin, 2001), a negative affect (Gill & Sharpe, 1999; Tandeter, 2006), and with whom there was little sense of making progress (Mathers *et al.*, 1995; O’Dowd, 1988). In contrast the expert patient traits identified in this study had a strong congruence with medical practitioners’ descriptors of an ideal patient; succinct, knowledgeable, rational and non-emotional (Hauser, 1981; Wilson *et al.*, 2006). Previous studies suggest these characteristics enable a shared language and greater mutual understanding (Carlisle *et al.*, 2005), and less time required in consultations (Deveugele *et al.*, 2002). Whilst the majority of participants in the study had developed these without attending a self-management course the findings suggested that in many ways these characteristics were reinforced by the EPP and to a lesser extent the BFC.

The most overt strategy of both programmes was to instil systematic approaches and enhancement of participants’ knowledge. Action planning and the setting of weekly goals for review was an integral part of both the BFC and EPP course material. Such strategies are seen as an effective mechanism for self-efficacy (Farrell *et al.*, 2004) and teach individuals to set realistic goals that are more likely to be achieved (Bodenheimer *et al.*, 2002). The ultimate aim of action planning was to routinise self-care practices and as a tool was popular with EPP participants who often kept up the process post course. Actively accessing information from sources such as reliable web sites and non-NHS sources of help was encouraged during the EPP but not during the

BFC. Whilst a more pedagogic approach to information giving within the BFC resulted in scientific knowledge being given to participants it seems unlikely that as adult learners this was likely to lead to active learning (Brookfield, 1986). With its emphasis on technical knowledge, the BFC was less effective than the EPP in engaging with people in a contextually meaningful way (Barry *et al.*, 2001; Mishler, 1981).

The EPP inherently promoted succinctness via the inflexible time limits kept on each topic. However, whilst there was limited time on topics such as anger, fear and depression, the encouragement and modelling of peer support by the lay tutors provided a strong element of emotional support for participants. Thus the EPP instilled expert patient traits and in addition appeared to provide a non-medical arena for emotional release (Barlow & Williams, 1999). Whilst it could be argued that this was an encouragement of expression of feelings, the concurrent content emphasising a rational approach towards patient- doctor encounters reinforced the discouragement of emotional expression within the medical consultation, thus enhancing the medical view of the expert patient (Barry *et al.*, 2001).

The contradictory nature of EPP content both promoting and inhibiting the acknowledgement and importance of the individual's feelings within the experience of chronic illness is indicative of the critiques that have been levelled at the programme. Wilson's (2001) policy analysis suggested that the EPP had a Foucauldian potentiality of medicalising self-care practices within an individual's previously hidden home life. This hypothetical seeping of medical power into all corners of an individual's life (Salmon & Hall, 2003) via the EPP has been linked with the continuing language of disease and paternalism still present within the programme

(Davidson, 2005) and it has been questioned whether the EPP can empower patients when so heavily reliant on the medical model (Fox *et al.*, 2005).

Salmon and Hall (2003) argue that this tension between empowerment and medicalisation is created by the combination of the new discourse of agentic patient with existing discourses. First, there is the continuing biomedical, dualistic discourse of the separated mind and body with expert patients expected to self-manage their disease as a separate entity from the rest of their life. Second, the contemporary discourse of the biopsychosocial model and patient-centred medicine has created a situation where patients are expected to disclose details of their psychosocial life to the doctor and make behavioural changes for disease prevention and management purposes. Thus, empowerment becomes problematic when there is a focus on changing an individual's behaviour rather than societal structures (Anderson, 1996), with this study indicating that at the very least EPP graduates continue to face health professionals who are disinterested in dealing with active patients. It has been suggested that this disinterest stems from a tension between health professionals' sense of professional responsibility and accountability being threatened by increasingly active patients (Wilson *et al.*, 2006) and mechanisms such as the EPP over which they have no control (Blakeman *et al.*, 2006).

The findings of this study emerging from the data on the EPP strongly echoes the national evaluation of the EPP (Kennedy *et al.*, 2004; Kennedy *et al.*, 2005a; Rogers *et al.*, 2005). The national evaluation also highlighted the likelihood of such programmes reaching a predominately white, middle class population (Rogers *et al.*, 2005) and reaching minority groups has been an ongoing problem for the EPP (Griffiths *et al.*, 2005; Rogers *et al.*, 2005; Wilson & Mayor, 2006). In addition it has

been suggested that active self-management is such a complex set of skills (Thorne *et al.*, 2003) that generic approaches are unlikely to reach the depth required to develop these skills (Davidson, 2005). The national evaluation indicated that a number of participants, particularly those with diabetes, would prefer a condition specific approach in order to acquire detailed information (Rogers *et al.*, 2005). Nevertheless, whilst superficiality was often apparent within the EPP reported in this paper, it often served to fuel a thirst in individuals to find out more. What was more problematic and appears to be relatively unrecognised apart from a few commentators (Bury & Pink, 2005; Wilson & Mayor, 2006) are the effect of negative participants who either leave the programme before completion or disrupt a course's success. The optimum time for an individual participating in an EPP needs to be addressed (Wilson & Mayor, 2006) with Rogers *et al.*'s (2005) findings suggesting the majority of participants identified themselves as in the "recovery" phase of their condition. Consideration needs to be given to mechanisms for targeting potential participants who are neither entrenched or are already expert patients.

Nonetheless, despite the criticisms and potential pitfalls of the EPP this study did substantiate to some extent the claims regarding the potential of the EPP as a life-changing event (Expert Patients Programme, 2006). Individuals affected by long-term conditions need their experiences to be legitimized, particularly when issues such as fatigue and pain with no known organic cause are not amenable to objective measurement, hence lacking medical sanction (Broom & Woodward, 1996). Being led by a person with a chronic condition and being held outside of the medical arena (Barlow *et al.*, 1999) added to this legitimization process, with Rogers *et al.*'s (2005) national evaluation identifying the EPP as meeting an unmet need in giving a voice to these individuals. Isolation is a major problem for many, particularly elderly people

with chronic illness (Barlow, 1998) and for a number of participants within the study the EPP provided a significant source of support. Apart from the obvious cost benefits of utilising volunteers to facilitate the courses, their credible stories and the modelling of a desire to be in control acted as an important trigger for self-care (Thorne *et al.*, 2003) and were central to a course's success (Davidson, 2005; Kennedy *et al.*, 2005b; Rogers *et al.*, 2005). However, whilst the study findings suggest that the EPP is effective in empowering participants to develop active coping skills (Barlow *et al.*, 1998b) the question remains as to whether this empowerment remains at the individual level or has developed at a community level with a potential for challenging structures. Whilst the study indicates that the course content does indeed serve to reinforce an image of an expert patient as defined by the medical paradigm there is emerging evidence suggesting that the EPP is beginning to trigger a movement that has the potential to effect change within the NHS structure. Many of the participants in this study reported meeting up informally with course members on a regular basis post completion of their programme. Whilst the primary aim of this was to continue with a social network and thereby reduce isolation participants also described the continuation of narratives that explored perceived weaknesses in the health care system. At the time of the study these informal gatherings had not evolved into anything more formal such as a health consumer group (Allsop *et al.*, 2004), however other EPP groups outside of the study reported in this paper have developed into a patient-initiated health consumer group (Mayor, 2006). The Pioneer Group is an example of such and its original aims were to provide a mechanism to underpin the self-management skills learnt and enhance feelings of control over participants' long-term conditions. This is indicative of a collective illness identity with individuals developing a cognitive and emotional connection with others in a similar situation

(Brown *et al.*, 2004). However, this group is now at a state of development where there is an active desire to influence commissioning and service development (Mayor, 2006) suggesting the development of a politicised collective illness identity with embryonic links to a broader social critique of service delivery (Brown *et al.*, 2004). As illustrated by Williamson's (1999) Repression: Release: Response model of health consumerism, many people with chronic illness suffer repression and a realization that their voices are not being heard. The Pioneer Group appears to be at the next stage; release, with an identification of their interests and attempts to voice them in the health care arena. Currently this group is supported by the local Primary Care Trust, however if the collective action of this group continues to develop and increasingly challenges statutory services it will be interesting to note whether this support continues, and how the response stage of Williamson's model is enacted as either an acceptance of the group's requests or rejection.

The EPP provides the ideal arena for the development of collective identity (Allsop *et al.*, 2004) but as Department of Health papers on the EPP initiative focus on individual empowerment (Department of Health, 2001) any subsequent collective action may be an unintended outcome of the programme. Any joining up of the Pioneer Group with other similar groups may indeed be a catalyst for change, or conversely as Allsop *et al.* (2004) suggest be simply actors providing legitimacy for a process that inherently reinforces an agenda of self-care and continuance of bio-power (Wilson, 2001). Further research is required to map the development and evolution of health care consumer groups triggered by the EPP to determine the validity of the programme's claim for empowerment. In particular implementation of changes to EPP provision from PCTs to a Community Interest Company independent of the NHS (Lord Warner, 2005) merits evaluation of whether such an approach would enhance

community empowerment or serve to reinforce the divorce between lay-led self-management and health care professionals (Wilson *et al.*, 2006).

Conclusion

This paper has critically interrogated the existing critique of the EPP as a vehicle for resource saving and maintenance of bio-power. The paradoxical nature of the EPP has been revealed for whilst it is suggested that the course content and structure do serve to reinforce the bio-medical paradigm, there is a concurrent acknowledgement of the subjective self and experience of living with a long-term condition. In addition there is emerging evidence that the programme may also be triggering a health consumer movement, which as a lay-initiative gives further voice to the patient narrative. It is presently unclear as to whether post-EPP user initiated self-help groups will develop into an empowered consumer movement (Fox *et al.*, 2005) that has the potential to impact on policy, or simply adapts and conforms (McClellan & Shaw, 2005) to the current self-care policy agenda.

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