
MSc Lifelong Learning, Policy and Research
The Expert Patient Programme: a critical review

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First and foremost, the patient's journey is the patient's journey through life; we don't, I think, experience one minute "I'm being a patient and the next minute I'm being a person", much as the system might try and do that by taking my clothes away and putting me into a hospital gown. The journey is the journey of my life; it includes negotiating my way through a territory called disease, but it is part of the larger journey of life.'

Ian Kramer, an Expert Patient

'Education for life is ongoing emancipation.'

Monbiot (2001)

There is also a cost to society: an economic cost, through avoidable days lost from employment and the associated personal expenditure, and social cost through the risk of isolation and social exclusion. And there are the extra health and social service costs that arise from these broader costs to society.

The Expert Patient (2001) (p17)

'Users and their carers should have choice, voice and control over what happens to them at each step in their care.'

NHS Cancer Plan London: DH

'The NHS Plan sets out our ambitions to create a patient-centred NHS. Our vision is to move away from an outdated system towards a new model where the voice of the patient is heard through every level of the service, acting as a powerful lever for change and improvement. Our goal is to move away from a paternalistic model of decision making towards a model of partnership, whereby citizens have a greater connection with their local services, and have a say in how they are designed, developed and delivered.'

Shifting the Balance of Power: Securing Delivery London: DH

'Learning is like breathing: we do it all the time.'

Learning from experience trust

Lifelong learning and the Expert Patient Programme: a critical review

Introduction

In this paper I shall be considering lifelong learning policy with particular reference to a recent NHS initiative, the Expert Patient Programme. After describing the programme and justifying its choice as a lifelong learning initiative, I shall attempt to set it in the broader lifelong learning agenda. A review of the literature will inform this discussion which will include suggestions for improvement and a conclusion as to the success of the initiative.

The Expert Patient Programme

The Chief Medical Officer in England, Professor Sir Liam Donaldson, notes that people with chronic illness often have more knowledge than their clinicians about their own condition. 'With proper training', he suggests that this knowledge and experience can be 'turned into practical skills to enable the patient to play a bigger part in managing their own condition'.

The expert patient initiative was conceived as a part of the Government's commitment to place patients 'at the heart of healthcare' which is in turn, part of the transformational focus of the clinical governance agenda. Viewed in the context of the lifelong learning agenda, it may also be seen as much more than simply improving the quality of care.

In the White Paper *Saving Lives: Our Healthier Nation* (July 1999, the Government set out its new Healthy Citizens programmes to help people make decisions about health care. The Expert Patient programme is the final strand in this initiative and is designed to help people with chronic illness become key decision-makers in their own care. By encouraging people to take more responsibility for their own health, it was hoped that these individuals would be able deal more effectively with long-term illness.

The Expert Patient: A new approach to chronic disease management for the 21st century was published in November 2001 and elucidated the ideas proposed in the earlier document. Its aims to support the government's ambition to 'create a patient-centred NHS' (*Shifting the Balance of Power: Securing Delivery*) and sits comfortably in the 21st century paradigm characterised by the desire to exemplify the 'key values of humanity, justice, equity and respect' (Stanton, 2003). The programme also forms a part of the government's Healthy Communities initiative, set out in the *NHS Plan*. Such a programme, together with other initiatives to support patients and improve the quality of care provides an opportunity to develop 'self efficacy, that is, an enhanced sense by an individual of how much they can cope with and achieve' (Wilson, 1999).

The writers of *The Expert Patient* set out (on page 7) their vision for the future role of patients with chronic disease:

- many more patients with chronic disease will improve, remain stable or deteriorate more slowly;
- many more patients can manage effectively specific aspects of their condition (such as pain, complications, medication use);
- patients with chronic diseases are less severely incapacitated by fatigue, sleep-deprivation, low levels of energy and the emotional consequences of their illness;
- patients with chronic diseases are effective in appropriately accessing health and social care services and gaining and retaining employment;
- many more patients with chronic diseases are well informed about their condition and medication, feel empowered in their relationship with health care professionals and have higher self-esteem;
- people with chronic diseases contribute their skills and insights for the further improvement of services and as advocates of others.

'To enable people to achieve good quality of life despite having a chronic disease' is the fundamental goal of the change being sought by this report (*Expert Patient* p9).

Lifelong learning

The idea of lifelong education was first fully articulated in this century by Basil Yeaxlee (1929). Along with Eduard Lindeman (1926), he provided an intellectual basis for a comprehensive understanding of education as a continuing aspect of everyday life. Tight (1996) notes three key features of subsequent accounts of lifelong education:

It builds on and affects educational providers.

It extends beyond formal educational provision to encompass all agencies, groups and individuals involved in any kind of learning activity.

It rests on the belief that individuals are, or can become, self-directing, and that they will see the value in engaging in lifelong education.

(Tight 1996: 36 quoted in www.infed.org/support/handouts/lifelong_learning.htm)

Difficulties in distinguishing between education and learning may be resolved by viewing learning as a

cognitive process internal to the learner, that can occur 'both incidentally and in planned educational activities', while, 'it is only the planned activities we call education' (Merriam and Brockett 1997:6 quoted in www.infed.org/support/handouts/lifelong_learning.htm).

The Expert Patient programme does not, strictly speaking, fall within the rather narrower confines of current lifelong *education* policies; however, as suggested above, it is in the vanguard of what Strain refers to as 'the change in culture that lifelong learning engenders' (Strain, 2003). It may also go some way towards meeting Illich's requirements of a convivial institution (or society): where modern technologies serve 'politically interrelated individuals rather than managers'. (Illich 1975:12).

Such institutions are characterized by 'their vocation of service to society, by spontaneous use of and voluntary participation in them by all members of society (Gajardo 1994: 716). In many respects, Illich builds on the ideas of earlier writers like Basil Yeaxlee who recognized the power of association and the importance of local groups and networks in opening up and sustaining learning. This line of thought paves the way for the concept of social capital which is, of course, only partly to do with economics.

Failure to meet these requirements of society and of institutions may, however, give rise to Illich's (1973) concern that:

'Medical treatment is mistaken for health care, social work for the improvement of community life, police protection for safety, military poise for national security, the rat race for productive work. Health, learning, dignity, independence, and creative endeavour are defined as little more than the performance of the institutions which claim to serve these ends, and their improvement is made to depend on allocating more resources to the management of hospitals, schools, and other agencies in question.'

Ivan Illich Deschooling Society

The quotations at the beginning of this paper reflect both the aims of the Expert Patient Programme and the three main perspectives of the lifelong learning agenda which, although constantly undergoing subtle shifts in emphasis, can be summarised broadly as:

- personal
- social
- economic.

The Expert Patient Programme sits comfortably within this broader agenda, incorporating economic perspectives, as well as the humanistic, personal

development perspectives first promoted by UNESCO as 'lifelong education' in the late 1960s and early 1970s.

By giving patients 'choice, voice and control' (*NHS Cancer Plan*), the programme reflects the Utopian vision of lifelong learning set out by Delors (1996) in the UNESCO report as a means of promoting *social cohesion and democracy*. The Expert Patient Programme offers patients the possibility to realise their *personal potential* while enhancing awareness and understanding of critical issues in public policy (NBEET, *Lifelong Learning—Key Issues*, 1996 quoted in Nouwens 2002), thus providing the opportunity for them to become both better people and better citizens. Economic imperatives are satisfied by the resulting increase in social capital (through building up collective knowledge) as well as by increased effectiveness of both patients and clinicians through better use made of everyone's time.

It is possible that the Expert Patient Programme may be (or may become) an example of Williams (date?) idea of an 'ethics of care', intended partly to balance New Labour's preoccupation with paid work as 'the glue that binds society together' and 'the point of connection that individuals have to the wider society'.

The following framework, developed by Habermas and organized around work, language and the exercise of power, may be helpful in considering how these three perspectives influence lifelong learning in a holistic manner while guiding the production and sharing of knowledge.

• **Technical** cognitive interest relates to the use of knowledge in exercising predictive control over the world by leaving aside questions of values in order to objectivise natural processes and social processes like those involved in work, that produce the goods and services needed to maintain life and society. This cognitive interest relates to the economic view of lifelong learning.

• **Practical** cognitive interest relates to the use of knowledge in the subjective world of individuals and their meaning making required for practical consensual action, and for the preservation and expansion of culture and traditions that provide a base for mutual understanding. This cognitive interest relates best to the personal development view of lifelong learning.

• **Emancipatory** cognitive interest relates to the use of knowledge in sharing power over human activity and the capacity of individuals to reflect independently and responsibly on social activity and to develop a sense autonomy (Smith & Lovat 1990, p.

68). *This cognitive interest relates best to emancipatory views of lifelong learning.*

From Nouwens, 2002

<http://www.library.cqu.edu.au/conference/presentations/Nouwens.pdf>

With this framework in mind, together with the broader lifelong learning agenda (featuring understanding and discourse as the predominant models of cognition, according to Therborn (1999)), we can now go on to consider some of the issues that arise from an examination of the Expert Patient programme.

What exactly is an ‘expert’ patient?

Doctors, nurses and other health care professionals often comment that patients with particular chronic diseases often understand their disease better than they [the clinicians] do. Does this make the patient an expert? What constitutes expert knowledge? Patricia Benner, in her book *From Novice to Expert*, portrays the expert [nurse] as a reflective practitioner who works intuitively, drawing *almost unconsciously* (my emphasis) on a repertoire of context-specific paradigm cases. The book begins with a section about uncovering knowledge and looks at:

- Differences between practical and theoretical knowledge
- Knowledge embedded in expertise
- Extending practical knowledge
- Common meanings
- Assumptions, expectations and sets
- Paradigm cases and personal knowledge
- Maxims
- Unplanned practices.

However, recent writings on informal, practice-based theory suggest that there is a level beyond expertise that is characterized by mindful practice and informal theory building. At this level, the practitioner constructs informal theory out of practice, applies that theory back into practice, and reflexively modifies the theory as a result of the changed (clinical) situation, much as Kolb attempted to describe with his now-ubiquitous learning cycle, suggesting that learning is a process leading to the production of knowledge.

It may be helpful here to look at what Polanyi (1967) calls *tacit knowledge* – ‘that which we know but cannot tell’ (cf Benner’s unconscious expertise). However, as Eraut (2000) points out, a string of writers have explored how tacit knowledge can be made explicit (and how explicit learning can lead to tacit knowledge). Tacit or implicit knowledge underpins many of our interactions with people and situations. Because of its very nature, it is not

explored in any coherent way, and so this kind of knowledge can be self-perpetuating and lead to behaviour that is inappropriate, or not productive.

This is a compelling argument for the exploration of implicit learning (and attempting to make tacit knowledge more explicit). Once revealed, it can be tested and developed. Equally important, particularly for people with chronic illness, is to do the reverse, and make explicit knowledge tacit (similar to the idea of unconscious competence – the ability to touch type without being able to describe which key your third finger must hit or to respond to medical emergencies without having to think about what to do). It is important to be able to identify and articulate tacit knowledge and then to be able to use it appropriately. Seen in this way, theory and practice are two parts of the same process, and the theory-practice gap is closed.

If the Expert Patient programme can uncover tacit knowledge and transform it into explicit knowledge, and vice versa, then there is some hope for change, and epitomises the part of ‘the learning process that derives from and are formative in developing relations with others and with other groups: a relational good’ (Strain 2003).

In an ideal world, we might hope that reflection might even become reflexion: a new and more questioning attitude characterised by individual reflection must inevitably be the result of expectations shaped by the media, by society and by experience as well as by scientific and medical advances. If patients become better reflective ‘practitioners’, perhaps their clinicians will become more reflective in turn. Krishnamurti reminds us that

‘...without knowing yourself as you know your own face in the mirror, all other knowledge has very little meaning. Learned people who don't know themselves are unintelligent; they don't know what thinking is, what life is. That is why it is important for the educator to be educated in the true sense of the word, which means that he must know the workings of his own mind and heart, see himself exactly as he is in the mirror of relationship.’

<http://67.120.246.148/teachers/quotes/krimurqut.asp>

More reflective clinicians, working in the spirit of greater openness and co-operation with more reflective patients must have a cumulative effect on the body of knowledge created (and represented) by economic, political and social influences. This will in turn have an impact on the understanding and expectations of patients/people with respect to all aspects of life, including healthcare, and not excluding a spiritual dimension.

Vygotsky (1978) recognised the dynamic process of learning within an individual’s immediate context and suggested that the process of learning produces

further capacity for learning; in a similar way, reflection must produce the capacity for more reflection which, at a group level, must become reflexion.

However, set against this somewhat idealistic view of the mindful, reflective 'expert', and the potential for reforming society as we know it, we should not forget Ivan Illich's warning about experts and 'professionalisation' as set out in *Disabling Professions* (1977) and his exploration of the expropriation of health in *Medical Nemesis* (1975). The latter book famously began, 'The medical establishment has become a major threat to health'. The case against expert systems like modern health care is that they can produce damage which outweighs potential benefits; they obscure the political conditions that render society unhealthy; and they tend to expropriate the power of individuals to heal themselves and to shape their environment.'

Illich noticed that experts and an expert culture always call for more experts. Experts also have a tendency to cartelize themselves by creating 'institutional barricades', proclaiming themselves gatekeepers, as well as being self-selecting. Finally, experts control knowledge production, as they decide what valid and legitimate knowledge is, and how its acquisition is sanctioned. Thus knowledge is indeed power. In order for the power to be shared more equitably, people must extrapolate knowledge for themselves and set it in their own context.

Is it possible to conceive of a situation in which expecting patients to be experts on their own conditions may back-fire? Sharing responsibility and promoting patient rights are appropriate in early 21st century culture, but is there a danger that doctors may sit back, absolved of responsibility? Will expectations of patients be unrealistic? Is there a possibility, inherent in the 'competitive drive to increase national "performance"' (Strain, 2003) of setting up yet another arena for competition ('Is she a better patient than I am?')? Complete answers to these questions would require a crystal ball, but some of the possibilities are touched on later in this paper.

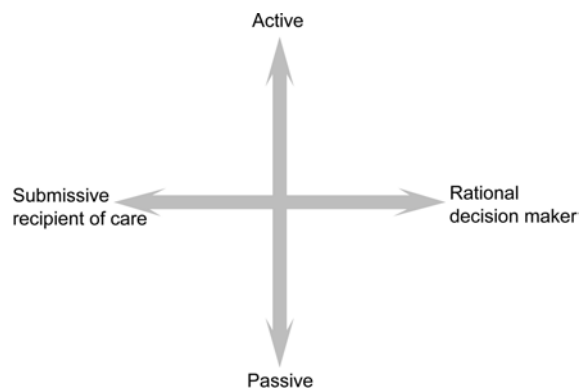
Working in partnership

The Expert Patient programme presents the possibility of combining the practical clinical knowledge that can be derived, as Eraut has shown, largely through informal methods of learning with the medical knowledge necessary to diagnose and prescribe accurately, currently held by the medical experts. Combined with the kind of awareness suggested by Benner and the humanity and respect that should be accorded to all patients, the resulting mix has powerful implications not only for improved care but also for social structures and the kind of democracy envisaged by Illich, Delors and others.

Fundamental changes to the NHS, intended to emphasise the patient's central role in the design and delivery of services, acknowledge that patients and professionals have their own areas of knowledge and expertise and need to work together. Angela Coulter of the Picker Institute (2001) has suggested the following areas of expertise:

- | | |
|-------------------------|-------------------------|
| • Patient | • Clinician |
| • Experience of illness | • Diagnosis |
| • Social circumstances | • Disease aetiology |
| • Attitude to risk | • Prognosis |
| • Values | • Treatment options |
| • Preferences | • Outcome probabilities |

It may be possible to map the progress of change by plotting these areas of knowledge and expertise on a matrix something like the following.



If we wish to go further down the route of plotting partnership, we might want to include Williams list of principles underpinning her vision of care:

- mutualism
- inclusive diversity
- autonomy
- voice

all of which are crucial to any discussion of partnership and would be located in the center of our matrix where true partnership would be found.

However, partnerships are, according to Wilson (1999), neither good in themselves nor a panacea, but rather one route to a better life for people living with long term medical conditions, especially when these partnerships allow patients to have a greater degree of control over their lives and access to services that are of better quality. Williams, quoting Wood 1991, reminds us that disabled people have not sought care, but rather independence and control. The concept of empowerment for (disabled) people

is based on choice and control, both of which the Expert Patient Programme aims to foster.

At a purely pragmatic (and economic) level, partnerships between patients and clinicians can also help make better use of health professionals' time.

True partnership must be based on equity and respect. It relies on informed patients who are able to contribute ideas to their care and treatment. It is ultimately relational and therefore, will not come about by focusing only on the patient. A number of constraints must be removed in order to make a real difference to patients and clinicians.

- The attitude of the medical profession which, although changing slowly, needs to adopt a different stance if it is truly to work in partnership with patients.
- The complexity of the healthcare systems which make it difficult for patients to access the services they need.
- Professional pressures on busy staff with little time to spend on forming partnerships with patients.

Partnerships can only be developed if there is investment by governments, if patients' capacity for self-care is increased, and if the role of patients' organisations is developed. The Expert Patient builds on the recommendations of Kate Lorig et al (1999) and Wilson (1999) that capacity must be developed within the NHS to put new policies into place. Building capacity requires investment in training and development and in structuring organisations so that employees have the relevant skills and competencies. This is as true of building partnerships with patients as it is for any other development in the NHS.

Sharing power

The medical establishment has been built upon the notion that 'knowledge is power'. A good deal of a particular kind of knowledge is required to offer the quality of care that westerners have come to expect. Unlike wisdom, knowledge is acquired from finding, digesting and using information which has, traditionally, been available only to a selected few: those who could pay for books and had time to read them. Medical knowledge has been the preserve of a privileged minority, imbued with an air of magic and mystique. Those who possess it have been respected and revered.

The notion of sharing that most valuable of commodities, information, has come about as the result of several trends in our culture and society: in economics, in ethics, in education as well as in healthcare. Emotional literacies (cf Golman's notion of emotional intelligence) are as important in shaping the expectations of 'consumers' of the health service as in forming part of independent knowledge (Strain 2003).

'The Expert Patient programme is not simply about educating patients about their condition or giving them relevant information. Neither is it based on a model of care whereby a health professional educates or instructs a patient and then measures success on the basis of patient compliance. It is based on developing the confidence and motivation of the patient to use their own skills, information and professional services to take effective control over life with a chronic condition.'

Expert patient p22

At last, the people who know most about their own lives and, often, about their own diseases - the patients - are encouraged to share their knowledge and experience and participate in decisions about their own treatment and care. Meanwhile, technology enables us to provide up-to-date medical information and the results of research to almost anyone almost anywhere via the Internet or other media-based strategies. Patients living with chronic disease need and deserve to be given the necessary knowledge and skills to enable them to work in true partnership with their doctors and clinicians.

In working towards partnership, medical experts would do well to heed the words of Confucious:

'To know what we know, and that we do not know what we do not know, that is true knowledge.'

Patients, on the other hand, do well to remember the words of Krishnamurti, that self-knowledge is the beginning of wisdom.

If both kinds of knowledge are acknowledged as important, power is automatically distributed more evenly and there is then the opportunity to realise Krishnamurti's vision that 'only through a complete change in the hearts and minds of individuals can there come about a change in society and peace in the world'.

Economics and social capital

So is the Expert Patient programme really driven by economics? Is it part of a plan to 'enhance the productivity and competitiveness of the national economy' (Strain, 2003) rather than as part of the more humanistic and altruistic vision more commonly associated with health care? The economics of care cannot be separated from the ethics of care, given the Government's current preoccupations with work and the value it accords to those who are able to engage with it, so clearly articulated by Williams (date) and Levitas (date).

On paper, the programme appears to support many of the principles underpinning Levitas' and Williams' views of how care should be, with promises of choice, control, autonomy, inclusion, and the opportunity to network, sharing experiences

with others and participating in a community of practice.

Shifting the responsibility for care onto patients and their carers may indeed reduce the cost to the health service and to society as a whole but the price is likely to be paid somewhere. Illich might warn against what he called 'counter-productivity' - this is the means by which a fundamentally beneficial process or arrangement is turned into a negative one. 'Once it reaches a certain threshold, the process of institutionalization becomes counterproductive' (*op. cit.*). It is an idea that Ivan Illich applies to different contexts. For example, with respect to travel he argues that beyond a critical speed, 'no one can save time without forcing another to lose it...[and] motorized vehicles create the remoteness which they alone can shrink' (1974: 42).

Health is everybody's business. (It is worth noting the use of the word 'business' here, and the close relationship between learning and earning.) There is growing evidence, particularly from the World Health Organization, that having strong social networks benefits health. In addition, when people are involved in making decisions which affect their lives, their self esteem and self confidence increases and this in turn improves their health and well-being. Cathie Hammond (2002) identifies benefits which are not dissimilar from the vision set out in the Expert Patient:

'Education is often an empowering and socialising process leading to long-lasting health benefits. The immediate psychosocial outcomes of learning – improvements in self-esteem, personal control and agency, interpersonal trust, anti-discriminatory attitudes, social support, and social political engagement – are central to the generation of behaviours, skills, and personal attributes that have early but lasting effects upon mental health, and cumulative effects upon physical health.'

The opportunity to gain greater control over one's life, to learn in a social group, to receive acknowledgement for knowledge and skills, to increase emotional intelligence (or literacy) and, ultimately, perhaps, to contribute to a community of practice, would seem to fulfil even the most stringent requirements of any lifelong learning policy. The Expert Patient Programme can thus be seen in part as a response to the contemporary pressures identified by Ulrich Beck's 'to create a life of one's own' while at the same time creating a life in society.

Regardless of whether the Expert Patient programme is driven by economic or humanitarian motives - and, of course, the issue is far more complex than an either/or dilemma - the social capital of both the individuals and the groups to which they belong will

inevitably increase. Bourdieu (1985) reminds us that 'the profits which accrue from membership in a group are the basis of the solidarity which makes them possible.' This reinforces the idea that socialised learning can and should provide an opportunity for what Argyris called 'double loop learning' to take place. The Expert Patient programme has the potential to raise hitherto hidden knowledge to the surface, and make it accessible to others (Eraut, 1994). The growth of a community of practice must be an inevitable consequence of the programme.

It is worth noting that the programme is characterised by 'unspecified obligations, uncertain time horizons and possible violation of reciprocity expectations' highlighted by Bourdieu as typical of the processes which bring about different forms of social capital (quoted by Portes, 1998). However, as Coffield (2000) points out, informal processes of learning can be as valuable as more conventional, formal methods of learning. This recognition paves the way for new ways of delivering and engaging with learning and in a redefinition of the environment of learning. Charles Leadbeater (2000) advises that 'more learning needs to be done at home, in offices and kitchens, in the contexts where knowledge is deployed to solve problems and add value to people's lives'. While there are elements of structured teaching and learning in the Programme, much of what patients learn will derive from their own experiences and those of other patients, and their ability to reflect on those experiences.

How successful has the programme been?

As of the end of 2003, more than half of the Primary Care Trusts in England have been involved in the Expert Programme, but there is, as yet, little research other than anecdotal findings. An independent national evaluation of the programme will be carried out by a Manchester-based team of researchers, although the criteria for evaluation are not immediately clear and are likely to focus on clinical outcomes. Initial feedback from patients has been generally positive. Although the programme has been running in the UK for only a short time, there is some evidence that such programmes do work.

However, the Chronic Disease Self-Management Programme has been successfully run by researchers at Stanford University in California for some 20 years. A highly structured programme led by trained volunteers who themselves live with long-term conditions teach people with chronic illness to deal with 'common issues such as pain management, stress and a need to develop coping skills on a daily basis.' (page 6 of *The Expert Patient*). A randomised controlled trial involving 952 patients revealed improvements in health behaviors and health status as well as fewer hospitalizations and days of hospitalization. (Lorig et al, 1999)

The core self-management skills in the CDSMP, which comprise the patient's 'toolkit' (listed on p5 Expert Patient) are:

- problem solving
- decision making
- resource utilization
- formation of a patient-professional partnership
- taking action.

It is clear that, whatever the context, these are skills for life!

Work carried out by Julie Barlow of Coventry University highlights the benefits of following such a programme:

- reduced severity of symptoms
- significant decrease in pain
- improved life control and activity
- improved resourcefulness and life satisfaction. (p26)

The Living with Long-Term Illness (Lill) Project has been instrumental in increasing the number of user-led self-management programmes for people with chronic long-term conditions and has seen positive benefits for participants, tutors and participating organizations (p26).

There is growing agreement that involvement by individual patients in making decisions about their care increases the effectiveness of their treatment. Service users are increasingly involved in planning and providing services and in monitoring and evaluating their outcomes, and their input is increasingly valued by healthcare providers and politicians (NHS Executive, 1996 and Coulter et al 1998).

However, there have been unforeseen problems in transposing knowledge (from a medical to a lay paradigm). Interpretations of knowledge about disease differ and an insular language results from patients' inability to use clinician's language. This very insularity allows and reinforces a consistent and corporate denial that prevents understanding and action on the part of the professions (Cooke, 2004).

Other problems include a sense that the NHS is simply paying lip service to the ideal of involving patients and of acknowledging patient expertise, while failing to address the real problems experienced by patients and carers (Clarke, 2003).

What more can be done?

Given that we are, almost all, patients at some time in our lives, and often from a young age, The Association of the British Pharmaceutical Industry (ABPI) emphasises the need to extend the Government's concept of the Expert Patient –

everyone should be better informed or more expert (From ABPI).

A number of initiatives have attempted to address this requirement, including

- The ABPI Electronic Medicines *Compendium*, launched to the public on the Internet in January 2000, provides healthcare professionals and patients with the UK's first comprehensive up to date guide to more than 2,500 prescription medicines.
- NHS Direct is a telemedicine service that provides guidance, health advice and information to 60% of the UK.
- The National electronic Library for Health (NeLH) is the first medical library providing equal access to patients and health care professionals, goes online in May 2000.

NeLH is a 'bold experiment in open-access medicine'. It intends to address what NeLH director Dr Muir Gray calls 'knowledge poverty and knowledge inequality by providing knowledge that has been through a 'quality filter' providing some assurance that the information available on the website is 'free from bias and conflict of interest'.

This open access policy would have been unthinkable a few years ago, but as NeLH director Dr Muir Gray says: 'The principle of giving patients less information is unsustainable for the 21st century. Many patients are better educated than the clinician. Furthermore, the patient may have only one problem, whereas the clinician has to deal with hundreds.'

The rise of e-learning and electronic media in general as part of a general re-evaluation of the learning environment (Segrave and Holt, 2003), is both timely and significant for the Expert Patient programme, despite being a contested area of learning theory development (Roffe, 2002; Clark, 2002). Even for patients (and carers) who are not disabled or have difficulty leaving their homes, the possibilities of access to up-to-date information 24 hours a day provides hitherto unimaginable opportunities to acquire knowledge and, by extension, for patients to realise their own power.

Although it is increasingly possible for patients to gain information via a number of different routes (including NeLH), there are few routes by which it is acceptable or even possible for patients to share their experiences. One possible route may be via digital patient stories (currently being developed by the National Clinical Governance Support Team) or websites such as that for the Database of Individual Patient Experience at www.dipex.org.

Conclusion

The Expert Patient Programme, especially in conjunction with these and other similar initiatives, has the potential to be a powerful stimulus for changing the way clinicians and patients work together and, as a result, could make a huge difference to patients' lives. When people who have been disadvantaged by long-term illness can recognise their potential and gain greater control over the lives, they will be more able to put something back into their social group.

By acknowledging the contributions patients can make to an understanding of chronic disease, and

reducing the mystique currently accorded to the medical profession the imbalance of power should be redressed resulting in changes at social, economic and personal levels.

The initiative is clearly based on the values of justice, humanity, equity and trust; it is equally clear that the skills patients learn are invaluable skills for life, not only for patients. It remains to be seen whether its implementation holds true to these principles and, in so doing, upholds lifelong learning policies for the general improvement of both individuals and society.

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