

The expert patient: a new approach to chronic disease management for the twenty-first century

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ABSTRACT – *The expert patient: a new approach to chronic disease management for the twenty-first century*, produced by the Department of Health, recommends the introduction of ‘user-led self management’ for chronic diseases to all areas of the NHS by 2007. The premise is that many patients are expert in managing their disease, and this could be used to encourage others to become ‘key decision makers in the treatment process’. Furthermore, these expert patients could ‘contribute their skills and insights for the further improvement of services’. It is hypothesised that self-management programmes could reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy. It is stressed that this is more than just patient education to improve compliance. Instead there should be ‘a cultural change ... so that user-led self management can be fully valued and understood by healthcare professionals’. I point out that these ideas, while welcome, are not particularly new. Achieving the desired culture change will not be easy.

Key words: CPD, chronic disease, expert patients, patient education, empowerment, asthma, diabetes mellitus.

The expert patient: a new approach to chronic disease management for the twenty-first century was produced by the Department of Health with input by representatives from professional organisations and patient bodies (an ‘expert patient’s task force’)¹. Like many such initiatives, the underlying idea is good, but the document is indigestible, repetitive, short on detail and filled with jargon and slogans.

The starting point is that:

Knowledge and experience held by the patient has for too long been an untapped resource. It is something that could greatly benefit the quality of patients’ care and ultimately their quality of life, but which has been largely ignored in the past. ...{Patients} can become key decision makers in the treatment process. By ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater control over their

lives. Self-management programmes can be specifically designed to reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy¹.

At an ‘Expert Patient’s Stakeholder Conference’ in July 2000, it was agreed that ‘user-led self management’ was a good idea, and that it could, among other things, reduce visits to GPs. One of the ‘key points’ that emerged from this conference was that:

User-led self-management programmes should be mainstreamed within existing policy frameworks. Resources need to be committed on a long-term basis to ensure the sustainability of self-management programmes. However, planning will need to ensure that development is in line with resources¹.

The final sentence suggests that money may not be available.

Areas covered by the document

The document is divided into five sections:

The Vision suggests a violent swing from the bad old days when patients were passive consumers to a new Utopia in which empowered patients will reap benefits including:

- remaining stable or deteriorating more slowly
- being less severely incapacitated by fatigue, sleep disturbance and low energy levels
- having the skills to cope with the emotional consequences of their disease
- contributing their skills and insights for the further improvement of services.

The Challenge states that an estimated 17.5 million adults in Great Britain have a chronic illness, the diseases listed being arthritis, asthma, back pain, diabetes, epilepsy, heart failure and multiple sclerosis. Also listed are diseases that can be disabling, embarrassing, stigmatising or can cause intense pain – a curious example of the latter is ulcerative colitis.

The Current Position suggests that the NHS is ‘not nearly as strong as it could be in meeting the needs of people with chronic diseases’. The exemplar recommended by the task force is the chronic-disease self-management programme developed at Stanford

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University, California, by Professor Kate Lorig, 'the leading international authority in the field'. Most of Professor Lorig's work has been in the field of arthritis, and her course, which is said to be used in Australasia, Europe, the USA and China, consists of six consecutive weekly sessions each of 2.5 hours. She and her colleagues have also written a number of patient-orientated self-help books².

In *Evidence and Experience* Professor Julie Barlow of Coventry University reviews the evidence on self-management, which is summarised in Table 1.

The Programme states that user-led self management should be incorporated into every part of the NHS, including Primary Care Trusts, Healthy Living Centres and NHS Direct. Lay-led self-management training programmes for patients with chronic diseases will be piloted between 2001 and 2004, and 'mainstreamed' in all NHS areas by 2007. According to the document, self-management tutors will be recruited from all sections of the community, there will be affordable flexible programmes to include those on the lowest incomes, and 'some older people', who may be wary of such media, will be encouraged to use new technologies such as the Internet¹. The authors are at pains to point out that they are suggesting something more than just patient education to improve compliance. Instead there will be 'a cultural change – so that user-led self management can be fully valued and understood by healthcare professionals'. It is, perhaps, germane to point out that Professor Lorig's subjects were volunteers who responded to advertisements, and, in various studies, between 79% and 92% were women.

Lessons from the treatment of diabetes

The *Evidence and Experience* section has only one reference to diabetes: to an article on computer-assisted self control in adolescents. As a diabetologist, I find this strange, since self management has been the shibboleth of our specialty for many years, although it has been more often honoured in the breach than in the observance. Nevertheless, intensive efforts have been made in the past 20 years by the Diabetes Education Study Group of the European Association for the Study of Diabetes. In 1987, Jean Phillipe Assal, one of the founder members, wrote:

Physicians cannot hope to treat conditions like hypertension, asthma, peripheral vascular disease and diabetes without the active collaboration of the patient. This collaboration is not born by spontaneous generation. The patient will only play an active part in the management of his disease if the doctor has also learnt a new role. A consequence of the doctor's assumption of the role of teacher will be an extension of both the traditional relationship between doctor and patient and of the time-honoured combat between doctor and disease into a more global encounter in which the patient is also actively engaged³.

An early example of an expert diabetic patient is Jack Eastwood, who developed diabetes in 1925 at the age of 13, and spent three weeks in a nursing home being 'stabilised'. At home

Table 1. Evidence for impact of self-management programmes on service use.

Health Problem	Impact of self-management programmes on care services
Chronic pain, arthritis	Reduction in number of visits to health professionals up to 80%
Arthritis, insomnia, asthma	Reduction in number of general practitioner visits up to 44%
Sickle cell disease, asthma	Reduction in number of hospitalisations (up to 31%) and length of stay (up to 50%)
Insomnia	Reduction in number of visits to specialists by 15%
Sickle cell disease, asthma	Reduction in number of accident and emergency department visits up to 39%

his diet was strictly controlled, and for two years all his food was weighed. In 1931, he won a scholarship to Oxford and took the first steps in what he regarded as a 'not less intelligent method of treatment'. He ate lunch in ordinary restaurants, played golf nearly every afternoon (such was university life in the 1930s!) and then had a four-course dinner in hall, eating whatever was necessary to give himself 65 g carbohydrate, 35 g protein and 30g fat. His basic regimen was two injections a day, but he tested himself before every meal and often gave extra insulin after lunch. Eventually he decided to eat normal meals and before each inject 'the amount of insulin that I knew from experience would be needed to cope with the food about to be eaten, due allowance being made for what I expected to be doing during the next few hours'. In 1935 he visited a specialist for the last time, and was discharged because he knew more about controlling his own diabetes than did the doctor. Several times he wondered whether he should switch from multiple injections of soluble insulin to 'something more modern', but decided that 'if it ain't broke, don't fix it'. By 1986 he calculated that he had given 50,000 injections, nearly all into the calf⁴.

Implications for self-management of chronic disease

If we look at this early example of an expert patient, we can see that his success was the result of a number of preconditions:

- basic education in the management of his disease
- the availability of objective ways to monitor his condition – urine tests and warning signs of hypoglycaemia
- an ability (and approval) to change his treatment as necessary
- a special sort of personality.

I suggest that these preconditions apply to the self management of all chronic diseases.

Education is necessary but not sufficient. It needs constant reinforcement and even then patients with a chronic disease suffer from tedium and burn-out. Simply handing patients a book or leaflet is not effective, but individualised instructions

are relatively easy to produce. For example, sending copy letters to patients both empowers them and acts as continuing education and encouragement⁵. This simple measure, which has now been recommended by the Kennedy Report, has been practised by a small number of doctors for the past decade, but has not been taken on board by the majority.

Some means of monitoring is necessary, ideally through an objective measurement, such as blood sugar, peak flow or prothrombin time⁶. Even the humble weighing machine can be used; patients with heart failure or nephrotic syndrome can weigh themselves every day and take a powerful diuretic, such as metolazone, if their weight exceeds a certain level.

No empowerment is possible unless patients have the latitude and explicit approval to change their treatment. Insulin is an obvious example, but emergency courses of steroids in asthma, changing doses of warfarin, giving injections of factor VIII in haemophilia and taking penicillin in the asplenic state are others. I can also envisage a situation where a patient with factor V Leiden could choose not to take warfarin regularly but could be given low-molecular-weight heparin to cover long flights and other thrombogenic situations.

Personality is also important. Professor Lorig found that a key element in her arthritis self-management programme was strengthening or changing psychological attributes⁷. Some people, like Jack Eastwood, want to take control of their lives, while others find it more comfortable to be 'mothered' by healthcare professionals. Empowering the latter group of patients will not be easy, although, as shown by Sheldon Greenfield many years ago, it is possible in the context of a research project⁸. A much bigger stumbling block is that many doctors and other healthcare professionals feel uncomfortable with the idea of empowering their patients. In the context of asthma, a recent study in a deprived area of London found that many GPs were suspicious of self-management plans and wary of allowing patients to use steroids at home⁹. Until a decade ago, patients with asthma in the USA, and probably elsewhere, were not encouraged to be proactive. Also, many diabetologists pay lip service to the concepts of self management and patient autonomy, and behave like tinpot Caesars in their clinics¹⁰.

Conclusions

So, will the vision set out by Professor Donaldson and the Expert Patient's Task Force work? The simple answer is 'no', unless there is a sea change in attitudes among patients and, more importantly, healthcare professionals. I worry that many of the projects in the list of references depend on charismatic individuals, and that it will be very difficult to generalise them. I know many diabetes units in which education is part of routine care, but which, when the leader leaves, have progressively abandoned these ideals in favour of the biomedical approach.

I applaud the idea of patient-led groups, but in my experience it is often the wrong people who volunteer to lead them. This problem is not addressed in the document, presumably because it would dent the premise that the patient is always right.

Key Points

By 2007, the Department of Health intends to introduce 'user-led self management' for chronic diseases to all areas of the NHS

Diseases for which this may be appropriate include arthritis, asthma, back pain, diabetes, epilepsy, heart failure and multiple sclerosis

For it to work, there will need to be a sea change in attitudes among doctors and patients

Studies with arthritis self-management groups suggest that such programmes work by strengthening or changing psychological attributes rather than teaching self-management skills

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