How effective are expert patient (lay led) education programmes for chronic disease?

Considerable hyperbole has surrounded the UK expert patient programme, and it has received considerable funding—but will its impact meet expectations?

Chris Griffiths
professor of primary care
Gill Foster
senior research fellow
Jean Ramsay
senior research fellow
Sandra Eldridge
reader in statistics
Stephanie Taylor
senior clinical lecturer in health services research, Centre for Health Sciences, Barts and The London, Queen Mary's School of Medicine and Dentistry, London E1 2AT

Correspondence to: C Griffiths
c.j.griffiths@qmul.ac.uk

Chronic conditions now account for 60% of deaths worldwide and are imposing an increasing burden on society and health services.[1] Self management programmes are commonly used to help patients learn the skills to manage their own conditions better.[2] The NHS in the United Kingdom, and countries in Europe (especially Scandinavia), Australasia, and North America have chosen specifically to use courses tutored by trained lay leaders, rather than health professionals such as nurses.[3] Considerable resources have been allocated to support and run such programmes. A major attraction for healthcare planners has been the expectation that such courses will reduce use of health care and will deliver long term cost savings.[4] More debate about the impact of lay led, self management programmes is needed. This article opens up this debate and examines the evidence that "expert patients" consume fewer healthcare resources, with particular reference to data from trials in the UK.

Involving patients in health care

Two main arguments drive the shift towards increasing patients' involvement in health care.[5] Firstly, it is unethical for patients not to be involved in decisions about their health and, by extension, for the public not to be involved in how care is organised. Secondly, greater patient involvement in the consultation may lead to greater satisfaction, and perhaps more importantly to better health. Patients' involvement has been championed by organisations like the Picker Institute (www.pickereurope.org), which monitor patients' experience of care and highlight deficiencies. Systematic reviews show that interventions can promote patients' involvement and possibly greater satisfaction, but the jury is still out on whether this leads to better health.[6]

Against this background, the UK government has promoted the idea of a patient centred NHS, with initiatives such as patient advisory liaison services, attempts to improve access to care, and "choose and book," a system that allows patients to choose the hospital to which they are referred by their general practitioner. Another initiative, the expert patient programme, was first announced in *Saving Lives: Our Healthier Nation*.[7] The programme is based on the work of Halstead Holman and Kate Lorig at Stanford University, who developed the idea of teaching arthritis self care by using lay tutors in 1979.[8] Early, small scale comparisons suggested that trained lay people and professionals could teach self care equally well. Lorig argued that the lay led model was attractive because lay educators were plentiful and relatively cheap and could help other people with the disease by "modelling" self care more effectively than healthy professionals.

Self care programmes

The success of the Stanford arthritis self management programme (http://med.stanford.edu/patienteducation/) spawned a generic programme, the chronic disease self management programme, which was adopted in the UK as the expert patient programme. Both consist of six weekly, lay tutored sessions (box) fostering self care skills through participative techniques such as modelling and action planning.

These programmes are based on Bandura's social cognitive theory of behaviour, which states that the key predictors of successful behaviour change are confidence (self efficacy) in the ability to carry out an action and expectation that a particular goal will be achieved (outcome expectancy).[8] Self efficacy is seen as an early step in causal pathways of behaviour change in self management programmes; increasing self efficacy (confidence) is a prerequisite for behaviour change which, through improved self management, may influence health and healthcare use. Many health services around the world have adopted this lay led model in the hope that it will deliver cost effective health gains.

Content of standard six week chronic disease self management programme

Session 1—Course overview; acute and chronic conditions compared; cognitive symptom management; better breathing; introduction to action plans
Session 2—Feedback; dealing with anger, fear and frustration; introduction to exercise; making an action plan
Session 3—Feedback; distraction; muscle relaxation; fatigue management; monitoring exercise; making an action plan
Session 4—Feedback; making an action plan; healthy eating; communication skills; problem solving
Session 5—Feedback; making an action plan; use of medication; depression management; self talk; treatment decisions; guided imagery
Session 6—Feedback; informing the healthcare team; working with your healthcare professional; looking forward.

Randomised trials of lay led self management programmes in the UK

Study	Intervention	Condition	No of patients	Outcome			
				Self efficacy	Psychological health	Generic health related quality of life	Use of health care
Barlow et al 200013	ASMP	Arthritis	544	Improved	Improved	Unchanged	Unchanged
Griffiths et al 200515	CDSMP	Various	439	Improved	Unchanged	Unchanged	Unchanged
Buszewicz et al 200612	ASMP	Arthritis	812	Improved	Unchanged	Unchanged	Unchanged
Kennedy et al 200714	CDSMP	Various	521	Improved	Improved	Improved	Unchanged

ASMP= arthritis self management programme, CDSMP=chronic disease self management programme.

Great expectations

In 2001 the expert patient task force, led by the chief medical officer, Sir Liam Donaldson, concluded that lay led self management programmes for chronic diseases (or long term conditions) would improve health status, slow the progression of disease, and reduce healthcare use, and that the NHS should invest heavily in the expert patient programme.[9] In 2003 the chief medical officer wrote an editorial for this journal asserting that the expert patient programme ushered in a new era of opportunity for the NHS.[10] He envisaged the programme reducing healthcare use and even mortality when he said: "Such people those with confidence live longer, are healthier, and are an example of how more assertive engagement with the health care system can improve both the length and the quality of people's lives." To date, the Department of Health has invested £18m (€27m; $36m) in the programme, with an explicit goal of providing the course to 100 000 patients.

Evidence for change in use of health care

Recently, a rapid review (commissioned by the National Institute for Health and Clinical Excellence) gave a cautious welcome to lay led self management interventions but pointed out that most evaluations were short term and set in the United States, and some of the data were uncontrolled.[11] A recent paper by Buszewicz and colleagues provides the longest duration of controlled follow-up to date (one year).[12] Of the four evaluations in the UK, two test the arthritis self management programme[12 13] and two the chronic disease self management programme, including the national evaluation of the expert patient programme carried out by the National Primary Care Research Centre in Manchester.[14 15] The results of these four studies are similar (table). The good news is that these programmes increase patients' self efficacy—in essence their confidence to change behaviour—and can lead to improved psychological health (although the effect sizes seem small). We found the chronic disease self management programme improved self efficacy in Bangladeshi patients, suggesting that it may be useful for ethnic minorities.[15] However, the changes in self efficacy are generally modest and it is unclear how much patients value improvements in self efficacy compared with, say, a reduction in symptoms or a gain in health related quality of life.

There are also important negative findings: generic measures of self rated health were unaltered in three of four studies, and more importantly, use of health care has remained stubbornly unaltered. The latter is a considerable disappointment because the expert patient programme has been heavily promoted by the UK Department of Health as part of a drive to reduce use of acute health care.

Several factors may explain the failure of lay led programmes in the UK to reduce the use of health care. Firstly, lay led programmes may do as much to promote consultation as they do to reduce it. The chronic disease self management programme teaches techniques to improve communication with clinicians, so patients may be encouraged to consult more. Secondly, any reductions in unscheduled (emergency) care may be obscured by increases in scheduled care. Thirdly, self management programmes may not be as effective at reducing healthcare use in settings such as the UK, which have universal healthcare coverage and well established primary care. It is unlikely that poor delivery of the programme in the UK is a cause since course tutors are assessed and course quality is strictly monitored. Three trials of the chronic disease self management programme in the United States show inconsistent effects on use of health care.[16-18] The much cited report of a 40% reduction in physician visits in the United States comes from a methodologically weak, retrospective comparison, in which arthritis patients in the community who had volunteered for self care education were compared with a group of arthritis patients with no explicit interest in self management who were under the care of rheumatologists.[19] Trials examining use of health care in the UK are unlikely to have missed an effect of this magnitude.

Testing questions

Although improvements in self efficacy and psychological health are welcome, these disappointing results can be compared with the impact of other professionally led self management or rehabilitation interventions in the UK. The six week heart manual programme uses a similar patient empowerment model for rehabilitation after a cardiac event.[20] Over a year, the programme improved psychological adjustment, especially in participants with high anxiety and depression scores at baseline, and it reduced visits to general practitioners and readmission to hospital. Psychological interventions for diabetes improve glycaemic control.[21] Exercise based cardiac rehabilitation reduces mortality.[22] Pulmonary

rehabilitation programmes produce clinically important reductions in breathlessness and fatigue in patients with cardiac obstructive pulmonary disease,[23] yet fewer than 2% of these patients in the UK have access to pulmonary rehabilitation each year.[24]

Why have these interventions had more impact than lay led programmes? Firstly, these programmes may be better targeted towards higher risk individuals, who experience greater morbidity. Secondly, key features of successful self management programmes include correcting erroneous health beliefs and teaching specific, clinical, disease management skills—for example, using a written self management plan for asthma.[25] Thirdly, cardiac and pulmonary rehabilitation programmes combine a structured exercise programme with self management advice; lay led programmes in their current form do not provide these additional components.

Questions about impact

Considerable hyperbole has surrounded the UK expert patient programme, and some patients attending courses have given powerful personal accounts of their benefits.

However, these accounts must now be seen in the context of the modest results of four well powered randomised trials in the UK. Although early results suggest that the programme can improve patients' confidence, questions remain about its impact on health in patients in the UK. How important is self efficacy as an outcome? How long do effects on self efficacy or other outcomes last? Do lay led programmes improve key measures of disease process such as glycaemic control, blood pressure, or weight? Should lay led programmes be targeted at patients with particular illnesses, perhaps with courses specific to these diseases, or at patients with particular psychological profiles? Could the expert patient programme be made more effective, perhaps adding slots for clinicians to teach clinical disease management skills? Our forthcoming Cochrane review should throw light on some of these questions,[26] but more well designed trials are needed to evaluate fully the contribution of lay led education programmes. The government should invest in such a programme of research in the same way it has invested heavily in implementing the expert patient programme.

Although general practice leaders in the UK may be tempted to include referral to the programme in future versions of the quality and outcomes framework, data so far suggest that this would be premature. The expert patient programme is switching from Department of Health funding to becoming a community interest company. As such, primary care trusts or general practice commissioning groups will need to pay for courses; they will need to consider carefully the opportunity costs of investing in this compared with other rehabilitation programmes for chronic disease.[27]

SUMMARY POINTS

In the United Kingdom the expert patients programme will be rolled out to 100 000 patients by 2012

Four randomised trials set in the UK indicate that although lay led programmes increase patients' confidence to manage their disease, they are unlikely to reduce either hospital admissions or the use of other healthcare resources in the NHS

Lay led programmes in the UK need evaluation before they can be recommended over other programmes with established impact

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