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spotlight on support for self care in the NHS

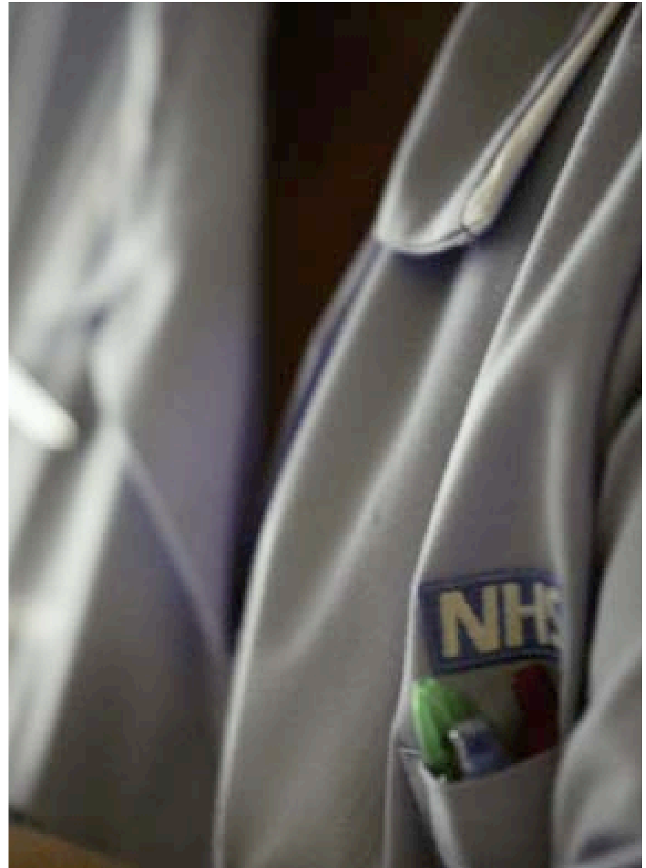
NATIONAL PRIMARY CARE RESEARCH AND DEVELOPMENT CENTRE

This issue of Spotlight examines the role of self care support for people with long-term conditions within the NHS. It has been written to inform debate about future service delivery and the ongoing research agenda about self care support. It is informed by research and reviews of the literature undertaken in the self-management programme at the National Primary Care Research and Development Centre, The University of Manchester.

Why is self care support important?

The need for a policy initiative to provide self care support for people with long-term conditions has been influenced by a number of factors including a steady increase in the proportion of people suffering from a long-term condition and the cost of providing chronic disease management. Self care support has become a central part of long-term condition management and plans for the NHS. It forms part of a wider agenda about public health; health promotion and primary care,[1] patient involvement, partnership and choice and the potential savings of improving self care support. The Wanless report[2] viewed supporting self care as one of a number of actions which could potentially save the future health economy billions of pounds. The current self care support policy has also been influenced by a broader national and international exchange of ideas, information and evidence about the self-management of long-term conditions.[3,4,5]

Current NHS policy envisages care for long-term conditions based around three tiers: case management for patients with multiple, complex conditions; disease management for patients at some risk, through guideline-based programmes in primary care;[6,7] and self care support for low risk patients (70-80% of those with long-term conditions). The Expert Patients Programme (EPP) was launched by the Department of Health in England in 2001 with its main aim to improve self care support in the NHS.[8] A key part of the EPP is a six week, lay-led self care skills course, which is an adaptation of the Chronic Disease Self Management Programme (CDSMP) developed in the USA.[9] In its pilot stage, the course was organised and delivered through Primary Care Trusts (PCTs) by people who had personal experience of living with a long-term condition (the course tutors). The courses are open to anyone with a self-defined long-term condition and are not specific to any particular condition.



Is the Expert Patients Programme effective?

The effectiveness of the pilot programme was measured in a randomised controlled trial which examined changes in self-efficacy (feelings of control and confidence in the management of long-term conditions), energy (a health outcome relevant to people with a range of long-term conditions) and health related quality of life (defined in terms of health status across five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression), as well as overall costs.[10] The programme had a marked positive impact on self-efficacy, a smaller impact on reported energy and improved patients' quality of life by providing them with the equivalent of one extra week of 'perfect' health per year. Although reductions in health services use were not statistically significant,[10] the cost-effectiveness analysis showed the programme is likely to be cost-effective because reductions in service use offset the costs of providing the lay-led self care skills course. Other recent studies of variations of the CDSMP in England support the general findings of our EPP evaluation,[11,12] although a study in an underprivileged, ethnic minority population did not show the programme to be cost-effective.

The need to look beyond the delivery of self care skills training

Evaluations of the process of implementation and of the experience of patients attending the course helped to explain the trial results and highlight the implications of running self-management skills training within the NHS. Several key themes emerged.

Effectiveness

Improved self-efficacy[i] and the group experience of meeting others were highly valued by participants. The course reinforced the salience of individuals' existing self care activities but did not bring about significant behaviour change. Social support from the group during the programme was also highly valued. The lay leaders were committed to the EPP and were generally appreciated by participants, although the perceived success of the group was dependent on their facilitation skills.[13] The benefits of a community delivered course may be difficult to replicate within traditional health service settings.

Implementation and reach

Whilst clinically and cost-effective, the reach[ii] of the EPP has remained limited[13] and reaching more diverse and disadvantaged groups has been a challenge for CDSMP courses here and elsewhere.[14] The lack of fuller patient and professional engagement with the course is likely to be linked to the dislocation of the course from other types of chronic disease management and consultations being provided in the NHS.

In its pilot phase the course generally attracted people who already viewed themselves as good self-managers and socio-demographic data has shown that nationally, EPP participants appeared to be better educated, live in better housing (more affluent) and are more likely to be female, than respondents to the 2003 Health Survey for England who reported at least one long-term condition.[13] Yet, it is people from disadvantaged communities who may stand to benefit most from the course and if additional efforts are not made to recruit people from these communities self care support training may act to increase rather than reduce inequalities. Generic courses are hard to market if they are not targeted at a specific group of people suffering from a particular condition and are unlikely to suit everyone. Self-management initiatives need to acknowledge the diverse nature of people suffering from specific conditions who might benefit from self care support and it seems important to ensure a range of provision.

The location and embedding of self care support within health service settings also requires attention. Impacts of the EPP course on health service utilisation may have been limited because demand for many NHS services is, to a degree, 'supply led' (e.g. initiated by health care professionals for ongoing tests, routine monitoring and repeat prescriptions) and also because the EPP was not designed to fit in closely with existing NHS provision - professional and organisational ways of working with long-term conditions. Whilst for obvious reasons there has been a great deal of focus on a national programme of self care skills training, there has also been a long tradition of alternative models of self care support which have continued to develop and may be more effective and acceptable than the self care skills training course and meet a range of different needs at different stages in a persons' condition (e.g. Lewin et al 2002[15]). At NPCRDC we have been developing and testing a model designed to integrate patient focussed self-management within existing NHS contexts and health professional ways of working. A system of self care support better integrated with the health service may overcome some of the limitations of the EPP. Engaging patients and clinicians in a shared approach to self-management within a supportive health service context may be more effective than self care skills training delivered outside mainstream health services.

The Whole Systems Informing Self-Management Engagement Approach

The whole systems informing self-management engagement (WISE) approach which we have developed and evaluated using a range or research methods (randomised controlled trials, economic evaluations and nested qualitative studies) is designed to engage self-management activity and action at three levels: improving patient information by drawing on peoples' existing skills and ways of living with a long-term condition; training health professionals in ways to provide support and guidance; and improving access arrangements to services and sensitising systems to be more responsive to patients.[16-31]

Research on the WISE model[16] shows that:

- information can be effectively improved to incorporate patient experience and expertise alongside medical information about management and treatment;[18]
- clinician training in patient-centred consultation skills and shared decision making with patients is acceptable and appropriate and leads to positive outcomes; [23,27, 28,29]
- health services systems which are better aligned to patient practices of self-management are generally well received; [24]
- an integrated approach leads to significant reductions in health service utilisation (without evidence of an adverse effect on patient outcomes).

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i Effect size for self-efficacy = 0.44, and for energy = 0.18. In general an effect size of 0.8 is high, 0.5 is medium and 0.2 is small.

ii 'Reach' is defined as the number, proportion and representativeness of individuals who participate in a given programme.

The WISE model[iii] (Whole system Informing Self-management Engagement)

	Patient	Professional	Structure
	↓	↓	↓
Strategy	Improve information	Change professional response	Improve access to services
	↓	↓	↓
Specific method	Work with patients to develop information that is • relevant • accessible • uses a combination of lay and traditional evidence-based knowledge	Promote flexibility in professional response through • a patient-centred approach • the negotiation of a self-management plan with patients	Change access arrangements • use patient/professional contacts as a means of complementing efforts in order to maximise the effectiveness of disease management • allow patients to self-refer based on self evaluation of need for advice

Box 1 The WISE approach in Inflammatory bowel disease - the RCT

The objective of the RCT was to determine whether the "whole systems approach" - which includes interventions at the patient, the professional and the service levels - altered patients' abilities to self-manage their condition, and whether they made more appropriate use of health service resources. The RCT had two arms and outcome measures were recorded at baseline and at 12 months. The intervention included:

Providing patients with information.

- Guidebooks on ulcerative colitis and Crohn's disease were developed with patients prior to the study.[24,25] The guidebooks were designed to support self-management by: including quotes from patients about the way they managed their condition; giving details about the pros and cons of different treatment choices; including a record book section where a negotiated self-management plan could be written and a food and symptom diary could be maintained.

Professional and organisational support

- Flexibility in professional response was promoted through a patient-centred approach provided by consultants trained in its methods. The two major components of a patient-centred consultation for inflammatory bowel disease were taken to be: addressing the impact of the disease on the patient; and establishing with the patient what treatment works.
- Initial and continued patient-centred professional contact as a means of negotiating and executing a self-management plan.
- Open access to outpatient clinic appointments with no more fixed appointments following negotiation of a self-management plan.

The main findings from the RCT were that the intervention resulted in significantly fewer hospital visits without change in the number of primary care visits. Immediately after the intervention consultation, patients felt more enabled to cope with their condition, but satisfaction with the consultation did not improve significantly. The intervention produced no change in quality of life and did not raise anxiety. The intervention group reported fewer disease relapses. Economic analyses favoured self-management over standard care.

iii http://www.npcrdc.ac.uk/WISEApproachSelf-management.cfm

Lessons from evaluating the WISE model

Patient level - Interventions for self care support need to be sensitive to, and negotiate ways of, self-managing which acknowledge the following:

- People's existing established strategies to manage life with a long-term condition. Self care support interventions should build on these and people's existing perspectives about their condition;
- The point people have reached in their trajectory of living life with a chronic illness i.e. how the condition changes with time; the possibility of relapses and recoveries; and varying needs for support and information from family and health professionals;
- The patient's existing social network, support systems and access to resources both inside and outside the health and social care system.

Professional level - At the professional level, there is a need to consider what happens during consultations and what can be done to improve the desired outcome of adequate and effective self care support.

- Improving the content of consultations through better training to provide professionals with strategies they can draw on as they attempt to negotiate care plans whilst respecting and acknowledging patients' own knowledge and experience of their illness;
- Acknowledging the differing values and perspectives of the health professional and patient;
  - A tension exists for GPs between valuing patient autonomy and encouraging self-management, and their need to address their own professional responsibility. Although GPs may value a shift towards increasing patient involvement, this is not necessarily straightforward and it is likely to take more than confidence to share some control and responsibility with the patient. More specific strategies and guidance within the consultation need to be developed and this is the focus of ongoing research work at NPCRDC.
  - Rather than using the term self-management, GPs tend to refer to valuing the development of a partnership approach to chronic disease management. Defining and negotiating the boundaries of care appear to be important elements in professional support for self-management in general practice (i.e. encouraging self care and experimenting within certain parameters).[26]
  - Being aware of the context of the consultation and which aspects are outside the control of the health professional.
  - There is a danger of clinicians proposing conservative, risk averse self care strategies, such as only focusing on compliance with medication, if contracts and targets make health professionals resistant to allowing patients latitude in their self-management practice.

System level - The way health systems are organised, for example lack of flexibility in the system and personnel who are unresponsive to the access requirements of self-managing patients, has an impact on how patients accept and adapt to changes in access arrangements. Past experience of engaging with health systems may make patients diffident and unsure of new arrangements which seemingly put them in control, when in the past things have been determined solely from the supply end of service arrangements. Face to face discussions with patients about the meaning of this shift will be important. The organisation of clinicians' work so that they have time to introduce self-management material and strategies 'up front' is likely to be crucial to professional and patient engagement in self care support.

- The dissemination and access to knowledge within the system could be improved. Staff should have up-to-date information to allow them to direct patients to support groups or self-management programmes. Plans to introduce information prescriptions from within primary and secondary care may give patients access to more appropriate information sources;
- There is a need for integrated working with social services and voluntary and community agencies;
- Opportunities should be in place for health professionals to attend self care support training programmes, such as motivational interviewing and cognitive behavioural therapy;
- Locating and running self care support interventions from within the health care system is likely to have the biggest impact on the utilisation of services.

Implications for implementation of self care support in the NHS

1. Strategies promoting self-management need to be embedded into routine service provision for chronic disease management. The WISE model may be a useful model for achieving this because it takes into account the need to intervene at three different levels, the patient, professional and organisational levels.
2. Health professionals require extra time and training to help them provide effective self care support, so that their consultations can focus on achieving shared responsibility and decision making.
3. There is a need to ensure that self care interventions are designed to complement people's previous experience of self-management and their existing social networks and systems of supporting everyday living with a long-term condition.
4. Access to clinics for those who are self-managing should be flexible and greater use could be made of shared care approaches between primary and specialist centres.

5. A plurality of resources are required to offer to patients in order to ensure they are given the level of self care support they require and to uphold the principle of patient choice.
6. Developing and locating self care support interventions in primary care settings is likely to be more effective than delivering self care skills training outside of main stream health provision. Primary care acts as the interface between lay-provided care and formal health care, and is the point in the system where most patients receive chronic disease management on a long-term and continual basis.

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