

# Support for self care for patients with chronic disease

**Anne Kennedy, Anne Rogers, and Peter Bower** argue that effective self care requires fundamental changes in professional attitudes and the way health care is delivered

Effectively managing long term conditions and the burden they place on patients, professionals, and services is a major focus of current health policy. Support for self care is increasingly viewed as a core component of the management of long term conditions.<sup>1</sup> However, despite the enthusiastic promotion of self care, randomised controlled trials often show modest benefits.<sup>2</sup> We examine why current initiatives fail to deliver and suggest what needs to be done.

## Potential benefits of self care

Self care is defined as the actions individuals “take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents.”<sup>3</sup> The potential benefits of self care are substantial. According to the proponents of the chronic care model (one of the most comprehensive models of care for long term conditions): “All patients with chronic illness make decisions and engage in behaviours that affect their health (self management). Disease control and outcomes depend to a significant degree on the effectiveness of self-management.”<sup>4</sup>

The Wanless report into NHS resource requirements identified effective self care as an essential part of the “fully engaged” scenario, which it predicted would bring about the greatest gains in public health.<sup>5</sup>

## Supporting self care in the NHS

In the United Kingdom, the Department of Health views service delivery for long term conditions in three tiers.<sup>6</sup> Case management is for patients with multiple, complex conditions, who get intensive, proactive care to avoid admissions. Disease management is for patients at some risk and involves guideline based primary care, facilitated by financial incentives. The final tier is self care support for low risk patients, estimated as 70-80% of those with long term conditions. A critical part of this support is the expert patients programme, a six session group intervention led by lay people who have experience of chronic disease and designed to improve skills and confidence in the management of long term conditions and to improve quality of life, enhance interactions with health professionals, and reduce service use.

Recent evaluations in the United Kingdom have shown expert patient programmes produce modest psychological improvements, but the effects on health outcomes and use of health services have been small.<sup>2</sup> This is because teaching patients self care skills is unlikely to be sufficient for effective self care.

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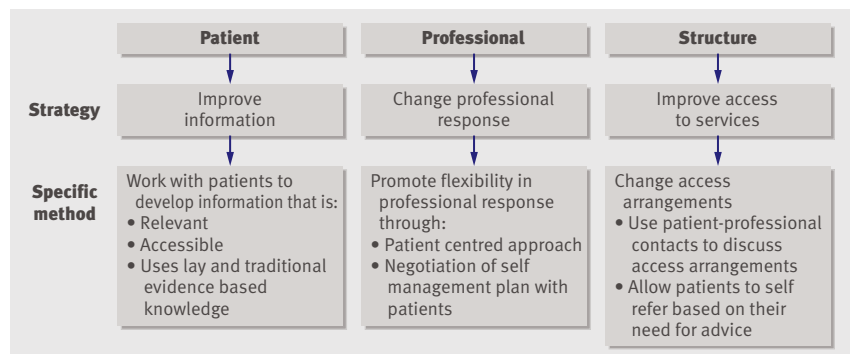
As the architects of the chronic care model argue, “self-management support can’t begin and end with a class.”<sup>4</sup> Effective support for self care requires two key changes in thinking:

- A whole systems perspective that engages patient, practitioner, and service organisation
- Widening the evidence base to acknowledge recent research on the way in which patients and professionals respond to long term conditions.

## Whole systems perspective

Research into improving the quality of health care indicates that multifaceted interventions are more effective than simpler ones and that enduring change requires a multilevel approach, where changes at different levels are interlinked to maximise the effect. For example, changing the behaviour of health professionals may require education of individual practitioners, audit among practice teams, and adoption of a total quality management approach by the organisation, supported by policies at the wider system level.<sup>7</sup>

Aspects of the whole systems approach can be identified in the chronic care model, which seeks to place self care in a wider context of professional behaviour change and community engagement.<sup>8</sup> Our centre has developed a model that applies the whole systems perspective to self care (the whole system informing self management engagement (WISE) model).<sup>9</sup> The model envisages informed patients who receive support and guidance from trained practitioners working within a healthcare system geared up to be responsive to patients’ needs (figure 1). As an example, a study based on this model might include interventions at all three levels:



Example of an intervention based on a whole systems perspective<sup>9</sup>

- Providing patients with an information guidebook based on current best evidence and patients' experience of managing their condition
- Training clinicians in patient centred consultation skills to manage the effect of the condition on the patient and establish a collaborative approach to decision making
- Changing service organisation to allow patients open access to outpatient clinic appointments and other sources of help.

Randomised trials of this model for inflammatory bowel disease found that the interventions significantly reduced hospital visits without changing the number of primary care visits.<sup>10-13</sup> Immediately after the intervention, patients felt more enabled to cope with their condition, and economic analyses favoured self management over standard care.<sup>10</sup>

#### Widening the evidence base

Even the intervention described above did not realise the full potential of self care. Interventions based on a whole systems perspective are clearly complex in nature and scope. Health services research is increasingly drawing on ideas from other disciplines to design and deliver complex interventions.<sup>14</sup>

The theoretical basis of many self care support programmes derives from psychological models, with individuals' beliefs and attitudes as key determinants of self care behaviour. Such models have a coherent theoretical basis and empirical support.<sup>15</sup> However, understanding about the management of long term conditions has also developed from social science research on health and illness.<sup>16</sup>

#### Taking the patient perspective into account

Patients with long term conditions face a wide range of challenges, including medical crises, symptom control, and social isolation. People often experience long term illness as a disruption to aspects of everyday life that

have been previously taken for granted. Adaptation to this disruption requires coping (developing a sense of coherence in the face of the changes associated with their condition), which in turn depends on strategy (mobilising resources to minimise the impact of the condition) and style (the way in which people represent illness, such as becoming socially withdrawn or making the illness a central part of their identity).<sup>17</sup> The ways that patients manage their conditions vary according to their background, socioeconomic circumstances, personal experience of living with a long term condition, local context, and domestic and family arrangements. Although self management training such as the expert patients programme can provide a range of skills, there is concern that they take insufficient account of patient variability.<sup>18</sup> For example, some patients with long term conditions develop stories that highlight their positive adjustment to their illness. The expert patients programme includes discussion of living wills, and this focus on death and dying can clash with patients' positive attitudes.<sup>19</sup>

Social science can be used to provide insights into the different ways in which patients self care. Interventions need to find ways of adapting to these existing strategies.<sup>19</sup> Effective support for self care is thus best delivered through a patient centred consultation with a trusted professional in the context of routine service delivery, rather than through classes.<sup>1</sup>

#### Encouraging professionals to change

It is often assumed that training is all that is required to increase professional engagement in self care. It is true that many professionals do not have strategies to support patient self care (such as motivational interviewing and cognitive behavioural strategies). However, this assumption ignores recent work highlighting the conditions under which professionals engage with new ways of working. Changing professional behaviour requires an understanding of the context in which they work and the values which they espouse.<sup>20</sup> New ways of working are more likely to become routine when they enhance the smooth operation of patient-professional relationships and do not disrupt existing relationships of trust.<sup>21</sup>

Although professionals broadly value self care, it raises tensions between patient autonomy and professional responsibility and the delivery of evidence based care. These tensions are reflected in professional concern about the need for monitoring of patients with long term conditions and for professional input into lay led courses such as the expert patients programme.<sup>22</sup> Professionals may place boundaries on patient participation and not engage with aspects of self care outside their professional perspective.<sup>23</sup>

A combination of incentives may be needed to change behaviour. General practitioners value developing relationships with patients and using their knowledge of the patient to intervene,<sup>24</sup> and self care support needs to be aligned with these core values and enhance professional autonomy. Financial incentives might be used to further encourage change.



### How do services need to be organised differently?

One of the presumed benefits of self care is reduced use of health services. However, healthcare services both enable and constrain self care.<sup>23</sup> Patients' use of health care is often driven by services (for example, tests and routine monitoring), and patients develop patterns of use which reflect the way that services are routinely provided. Self care interventions that seek to change healthcare utilisation will need to acknowledge the ways in which traditional service delivery has moulded patient behaviour. In our trial of guided self care for inflammatory bowel disease, fixed outpatient appointments were replaced with open access arrangements. Although many patients found the change to open access acceptable, some patients reported a sense of security from conventional arrangements, as they did not require the patient to initiate the request for medical help.<sup>23</sup>

New models such as polyclinics, which offer a wider range of services than general practices ([www.healthcareforlondon.nhs.uk](http://www.healthcareforlondon.nhs.uk)), may enable a more integrated approach to the management of long term conditions, where the philosophy of self care is inherent in the design of services rather than being implemented in a context that is more suited to professionally led care. Changes to service structure to support self care must be designed to encourage patient confidence and will require health systems to develop a coherent vision of self care support and the changed working practices required.

Support for self care clearly has the potential to improve the quality of care for people with long term conditions. All levels of the healthcare system could benefit from change to create the context in which self care can thrive.

**Contributors and sources:** AR is a sociologist and leads a programme of self management research. PB is a psychologist with an interest in the evaluation of self care interventions and their delivery in primary care settings. AK is a health service researcher with interest and experience in the development and evaluation of self care interventions. This article arose from reflections on the results of ongoing research in self care, and discussions with various stakeholders including academics, service managers, policy makers, and patients. PB wrote the original draft of the article, based on the extensive work of AK and AR. All authors then participated in redrafting. AK is the guarantor of the article.

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### SUMMARY POINTS

Support for self care has the potential to improve the management of long term conditions

Current interventions have only modest effects on patients' health and use of health services

One possible explanation is that interventions tend to focus solely on the patient

Interventions need to reflect the ways in which patients and professionals respond to long term illness

Approaches need to target patients, professionals, and healthcare organisations

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### Perspectives

Child protection casework traditionally operates on the assumption that the work is carried out from an "objective and professional" perspective where "expert knowledge" is attained from the "the facts" and the judgements that professionals make are "the truth" about a situation. This perspective renders largely invisible the reality that it is simply one human being, or a group of human beings, with their own particular worldview, values, and beliefs making these judgements about other human beings...Further, the

simple fact—which cannot, in our view, ever be overemphasized—is that what the statutory agency and its workers see and judge significant is often quite different from the perspective and priorities of the family.

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