

THE NEED FOR AN INTEGRATED APPROACH TO SUPPORTING PATIENTS WHO SHOULD SELF MANAGE

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ABSTRACT

The rise of lifestyle-related chronic disease in the UK and Europe has led to an increasing burden on healthcare systems. Much of the disease burden is recognised to be preventable or as having the potential to be reduced if citizens take a greater responsibility for their health and make changes to their lifestyles. Self management has been proposed as a key strategy in achieving this. Self management support has been a feature of the National Health Service (NHS) in England and Wales since the introduction of the Expert Patient Programme in 2002. Since its implementation there has been ongoing debate about the effectiveness of the approach and self management in general. Self management is still in its infancy and there remains a lack of evidence around the systematic implementation of self management support through an integrated pathway approach. This article gives a personal view of the role that self management has in modern healthcare and proposes what a integrated pathway approach may look like. Some of the main factors to consider in the implementation of self management support are discussed.

Key words: Self management, chronic disease, expert patients.

WHY DO WE NEED SELF MANAGEMENT SERVICES?

In Great Britain, as many as 17.5 million adults may be living with a chronic disease. Non-communicable conditions such as cardiovascular diseases, diabetes, obesity, and respiratory diseases, account for an estimated 86% of deaths and 77% of the disease burden in the European Region, as measured by disability-adjusted life-years.

Although life expectancy has been progressing rapidly over the last decades and was 76.4 years for men and 82.4 for women in the European Union in 2008, the average number of health life years has not been progressing. This stands at 60.9 for men and 62 for women resulting in an ever increasing burden on the NHS (WHO)¹.

This demographic change and the rapid rise of non-communicable disease has brought about the need for a radical rethink in health care and the role of the patient in care.

It has become widely recognized that for many people much of the disease burden is preventable and lifestyle related. In response, health care policy over the last decade² has started to focus increasingly on strategies that bring about changes in health related behaviours. One of the main strategies is the focus on self care and self management.

WHAT IS SELF MANAGEMENT?

Self management can be defined as; ‘The actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health, meet social and psychological need, prevent illness or accidents, care for minor conditions and maintain health and well being after an acute illness or discharge from hospital.’³.

Self management support is the response of health and social care organisations in terms of the services they put in place to enable people to self manage.

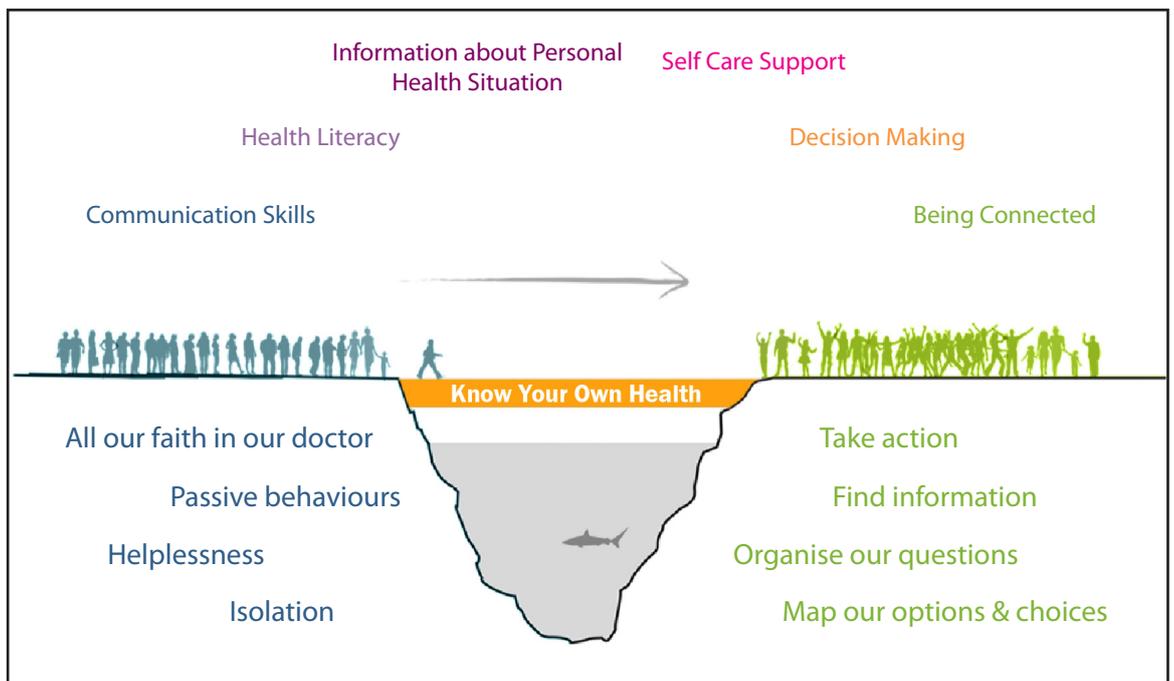
Self care and self management are often used interchangeably, however for the purpose of this article, the term self management will be used in the context of the management of long term health conditions, and self care for the management of minor illness and general health.

AIMS OF SELF MANAGEMENT SUPPORT

The main aim of self management support is to enable patients to have the skills, knowledge and expertise to make positive choices about their health care, and to make long term positive changes to health behaviours, such as maintaining a healthy weight, staying active and managing the emotional impact of the condition on their day to day lives. In short, to move from being passive recipients of care to a state in which they are fully engaged with their own health.

This journey is illustrated for patients by the diagram in Figure 1⁴.

Figure 1: The Patients’ Journey



OUTCOMES FOR SELF MANAGEMENT

A report published in May 2011 by The Health Foundation⁵ found that proactively supporting self management, and focusing on behaviour change, can have an impact on clinical outcomes and emergency service use. A focus on behaviour change is also a necessary component in facilitating the effectiveness of other support methods such as information provision.

There is emerging evidence that interventions that specifically aim to increase patients levels of self-efficacy or activation are more likely to produce positive outcomes in terms of behaviour change and health outcomes⁶.

Research outcomes have demonstrated the potential of self management programmes to enhance the quality of the doctor-patient relationship. Patients regularly reported improved communication with clinicians and other health care providers⁷.

The Danish Centre for Health Technology Assessment found that overall, most studies in the field indicate that supporting self management works. The level of evidence and results vary between different types of interventions and target groups, and therefore there are inconclusive findings⁸.

Researchers have also started to consider the wider benefits of self management support, including its social impact on people's everyday lives. Early findings from social return on investment (SROI) studies indicate that having access to self care programs can support individuals to become re-engaged with the local community as productive citizens with meaningful activities. This can take many forms including improved relationships with family and friends, engagement in volunteering, further education, or positive employment-related outcomes⁹.

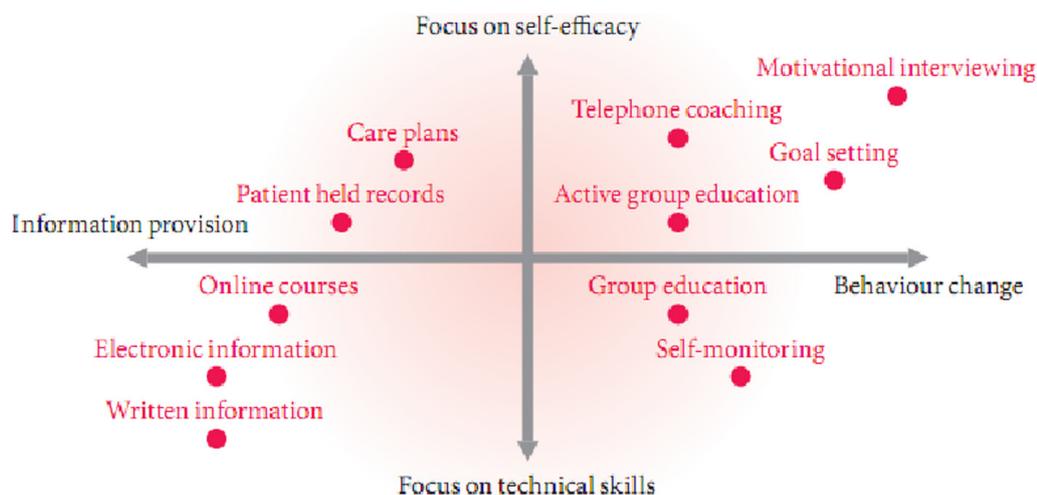
WHAT MAKES A PROGRAMME EFFECTIVE?

Much of the research has focused on specific programmes rather than what the key elements needed for an intervention to be effective may be. A meta-analysis in 2005 concluded that self management programmes for diabetes and hypertension probably produce clinically important benefits. However it was not possible to determine which elements of the programmes were most responsible for the benefits and this lack of research inhibits specification of optimally effective or cost effective programs¹⁰.

Self management interventions range from the simple provision of information to motivational interviewing and coaching as illustrated in figure 2.

The most effective self management approaches recognise that to achieve optimum health outcomes and quality of life, the person needs to develop skills and knowledge to manage a broad spectrum of issues. These may include the biological, mental, emotional and social impacts of disease, and are often referred to as bio-psycho-social approaches.

Figure 2. Continuum strategies to support self management – reproduced courtesy of the Health Foundation. Evidence: helping people to help themselves Health foundation 2011⁵



Some researchers have attempted to isolate the elements that make a programme effective by looking at the skills used by ‘activated’ patients and those who are successfully managing a long term health condition^{11,12,13}. A British Heart Foundation review¹⁴ of effective cardiac education and rehabilitation also identified some key components of the programmes that had good outcomes.

Drawing on these sources a list of the main components would include:

- An assessment of a patient’s rehabilitative needs: medical, psychological and social.
- Education as to the causes of the illness and those things that can help to ensure that the patient enjoys the best possible health in the future:
 - Problem solving - skills to deal with issues as they arise;
 - Decision making - making active choices around health and treatment;
 - Utilising resources - knowing what support is available and making use of it in an independent way;
 - Making sense of information - identifying conflicting messages, making effort to get consensus;
 - Taking action through goal setting - setting clear objectives and plans to change;
 - Ongoing support and review of these goals;
 - Developing effective partnerships with the care team and others;
 - Pacing - avoiding over and under activity;
 - Managing emotions.

IMPLEMENTING SELF MANAGEMENT SUPPORT PROGRAMMES

Probably the best known example of a structured self managed support programme in England is the Expert Patient Programme (EPP) which was first proposed in the Government's 1999 White Paper, *Saving Lives: Our Healthier Nation*. The White Paper set out the idea of the "expert patient" and postulated that confident knowledgeable patients would have improved health outcomes and use services more efficiently.

The programme was the subject of a randomised controlled trial which found it to be cost effective, based on an implementation cost of £250 per person¹⁵.

Since that time there has been a growing recognition that a more systematic and integrated approach needs to be taken in the implementation of self management support, if it is to have an impact on health outcomes on a large scale. The report into the Expert Patient Programme in England¹⁶ recommended much greater integration with clinical pathways and commented that there is not 'a one size fits all' approach.

There is currently no definitive integrated model for the provision of self management support. However there are some key objectives when considering how a service may operate optimally.

It is the author's opinion that a self management service needs to deliver the following objectives:

- Supports both a primary and secondary preventative approach and is ideally accessed through a single point of access.
- Uses evidence based approaches that support adults to take control over their own health and well being. Examples of these approaches include online behaviour change, telephone coaching and small group self care programmes, websites, smart phone applications, peer networks.
- Focuses on achieving *specific measurable* outcomes in relation to health behaviour.

Ultimately the service will aim to meet local priorities and may include: increasing the number of adults making healthy lifestyles choices, reducing the prevalence of unhealthy behaviours (poor diet and inactivity), improving the service users' levels of health literacy and ability to manage their health (activation), reducing hospital readmissions and unplanned admissions and improving key disease indicators such as glycosated haemoglobin in diabetes, and incidence of acute episodes.

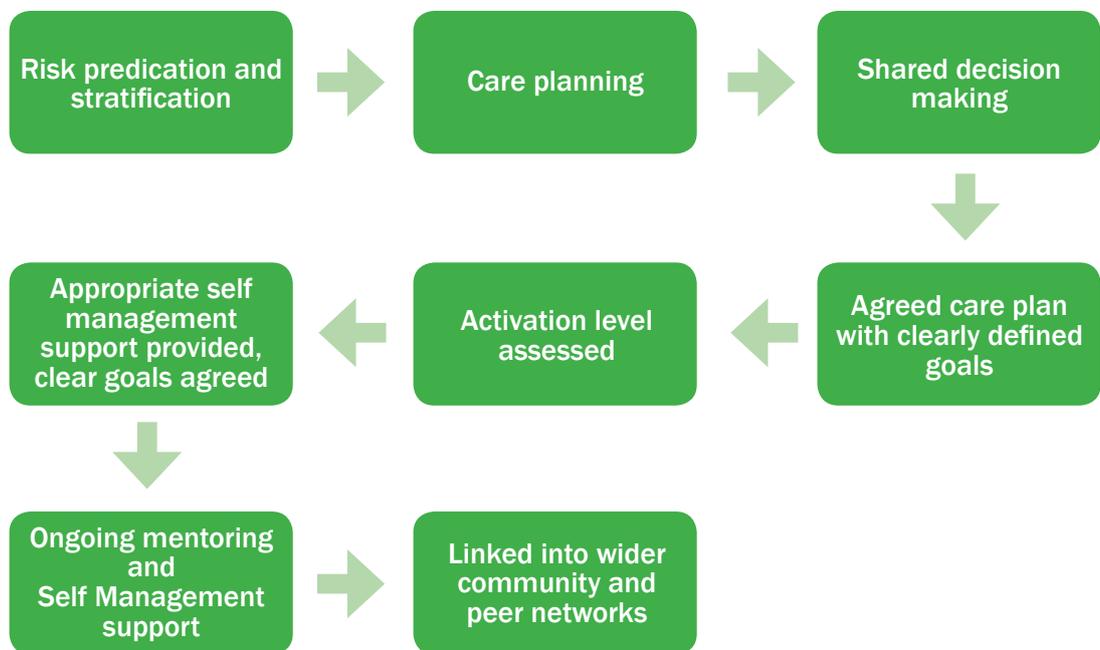
Self management services need to be based on clearly defined need and linked to clinical and local priorities. They should form part of an overall strategy for supporting long term health conditions. These then need to be translated into personalised self management support packages.

There are a number of steps needed to achieve this:

1. Risk prediction and stratification - identifying how many people in the local population would benefit from self management, i.e. those who are at highest risk of poor health and high service use.

2. Care planning - identified patients are engaged in the development of a care plan with their clinician with clearly agreed and identified priorities.
3. Shared decision making - treatments and care plan should be agreed in a collaborative way with the patient engaged in the goal setting and treatment choices resulting in a collaboratively agreed care plan.
4. An assessment of a person's ability to achieve agreed goals and treatment adherence.
5. Based on assessment and patient's confidence, appropriate self management support packages are put in place, focused on supporting the patient to achieve agreed goals.
6. Linkage to ongoing peer-support and wider community support networks.

Figure 3: The key elements of a self care strategy for long term health conditions



Self management programmes may be delivered by a variety of people including health care professionals, clinical psychologists and trained lay people who may be volunteers. To some extent, who delivers a programme is dependent on the outcomes required. Health care professionals are effective where information and support around treatments and medications are important, peer programmes may be effective where lifestyle change is an issue.

FURTHER CONSIDERATIONS

When implementing a self management programme, the skills of the people involved are a crucial factor. Their ability to facilitate, motivate and support people to optimise their potential is a key component of the outcomes achieved. All interventions are only as good as the people delivering them.

The full involvement of the care team is essential. A key drawback of the NHS expert patient programme in its early stages of deployment, as highlighted in the final report¹⁶, was the lack of support from clinicians and its lack of connection with local care pathways.

Patients attending early self management programmes came away with increased self confidence, keen to take more responsibility in managing their health condition. Unfortunately this positive attitude was not always reciprocated by their doctor.

To ensure that self management and self management support is effective, it is essential that the care teams are also supported in developing the core skills that enable changes in health behaviours and beliefs. The skills for health care professionals have been identified by Wagner *et al*¹⁷ as including, (but not limited to):

- Establishing an empathic clinician-patient relationship;
- Joint agenda setting for each consultation;
- Collaborative goal setting;
- Exploring ambivalence about change;
- Using problem-solving skills and systematic tools to support follow up of goals.

The 'Health Foundation' a UK based health charity (www.health.org.uk) has, over the last four years through their 'co-creating health programme', developed considerable resources and tools for clinicians who wish to practice in a way that optimises a person's ability to self manage.

FOLLOW UP

Finally, what happens after a self management programme finishes is almost as important as the programme itself. Many of the people attending the programme will have made significant changes to their lives. Some will have been living with depression as a result of living with a long term health condition and subsequent social isolation. During the period that they are actively supported, they will have experienced a supportive environment and begun the journey to improving their health and well-being. It is important to consider what longer term support may be put in place so that the possibility of relapse into former behaviours is reduced. There are now very good web based communities and tools that can be used to allow people to stay in touch with their peers. In addition the courses may provide introductions to local support groups and other local patient groups.

RESOURCES

There are now considerable resources in the UK for anyone wishing to implement self management support. The following are useful places to start:

Evidence and materials - The Health Foundation resource centre at <http://www.health.org.uk/resource-centre/new-sms/>.

For training and development there is a national network of NHS trained self management trainers www.talkinghealth.org.

For web based self management support www.selfmanagement.kyoh.org

Quality standards - Quality institute for self management education and training (QISMET) www.qismet.org.uk

Conflict of Interests: None

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