Improving self-management for patients with long-term conditions

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Summary

An increasing number of people in England are living with long-term conditions. These conditions cannot be cured, but can be managed through education, health promotion, medication, therapy and self-management. Self-management involves people taking responsibility for their own health and wellbeing, as well as learning to manage any long-term illnesses. Nurses play a pivotal role in providing advice, guidance, education and support to people living with long-term conditions. Self-management is important as it not only benefits the patient, but also provides wider opportunities for community and specialist nurses to use and develop their clinical and interpersonal skills.

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Aims and intended learning outcomes

This article aims to explore some of the nursing implications associated with the rapid increase in the number of people living with long-term conditions, as well as addressing the nurse's role in supporting patients to self-manage their conditions. After reading this article and completing the time out activities you should be able to:

- Understand the personal and economic burden of long-term conditions.
- Recognise the benefits of self-management in enhancing the patient's quality of life.
- Identify your role in supporting patients in self-management.
- Implement strategies that will support government initiatives aimed at enhancing self-management skills.

Introduction

The British Medical Association's (BMA) vision is for people with a long-term condition to 'own and control their condition' rather than the condition dictating how they lead their lives (BMA 2007). In England, an estimated 15.4 million people have a long-term condition (Department of Health (DH) 2009a). Long-term conditions may include diabetes, asthma, arthritis, hypertension, some respiratory conditions and some mental health problems, such as depression and schizophrenia. It is estimated that 85% of deaths in the UK are from long-term chronic diseases, with 36% of all deaths resulting from cardiovascular disease and 7% from chronic respiratory disease (European Cardiovascular Disease Statistics 2008).

The personal and economic burden of long-term conditions is exacerbated by additional health and lifestyle factors. People with two or more long-term conditions are more likely to be obese, eat less healthily and smoke than people with one or none of these conditions (Maskell 2007, Scottish Government 2007). Such co-morbidities affect individuals' quality of life, and lead to huge cost to the NHS. Furthermore,

since these illnesses are associated with ageing, the prevalence of long-term conditions is expected to rise with an increasing ageing population. It is estimated that three out of five people aged over 60 years live with a long-term condition (DH 2009b).

Time out 1

Take some time to reflect on your current patient caseload and answer the following questions:

- How many of your patients have one or more long-term conditions?
- How does your caseload differ from that earlier in your career?
- If you are relatively new to nursing, how do you envisage your caseload changing over the next few years?

If you find it difficult to evaluate a present or future change in your caseload, ask a more senior colleague how practice has changed over the years in terms of long-term conditions.

While improved longevity is a recognised feat of the health system, a shift has been made towards prolonging 'active life expectancy' (Katz *et al* 1983). Active life expectancy was defined by Abraham Lincoln: 'In the end, it's not the years in your life that count. It's the life in your years' (Blaisdell 2005). However, at present, this is often not the case, but active life expectancy could improve through education and health-promoting activities that encourage self-management initiatives. Quality of life has become as important as length of life, hence the growing popularity of self-management initiatives.

Time out 2

Reflect on your own knowledge of self-management and ask yourself the following questions:

- What does the term 'self-management' mean to you?
- How would you define self-management for the general population?
- How would you define self-management for people living with long-term conditions?
- Are there any fundamental differences between these definitions?

Self-management

Self-management involves individuals taking responsibility for their own health and wellbeing. For people living with a long-term condition self-management can become a more fundamental part of their everyday lives, to ensure independence, self-worth and the ability to lead as active a life as possible. For high-risk patients with such illnesses, self-management is essential to prevent further complications. This has been acknowledged within government policy, with initiatives being put in place to enhance the self-management skills of people with long-term conditions, such as the expert patient programme (DH 2001). Nurses are well placed to implement such policy, promote self-management and educate patients on the quality-of-life benefits of self-management. Training packages are available for health professionals, helping them to develop the key skills in self-management promotion (Working in Partnership Programme 2010). Taking part in these courses can be incorporated into continuing professional development (CPD), with CPD credits being provided for participation.

To describe government self-management initiatives, the Prime Minister made a commitment in January 2008 to develop a patient's prospectus outlining how people with long-term conditions can access a range of self-management services. *The Patients' Prospectus – 'Your Health, Your Way – A Guide to Long Term Conditions and Self Care'* (DH 2008a) set out the support that patients with long-term conditions could expect from April 2009.

Time out 3

Access the document *Your Health, Your Way – Your Guide to Long-Term Conditions and Self Care* at: www.nhs.uk/yourhealth/Pages/Homepage.aspx and identify the minimum support patients can expect for managing their long-term conditions. Do you feel that patients in your service are receiving this support? If so, are there any ways that you could try to maximise this? If not, are there any steps you could take to ensure that this minimum level of support is being provided?

From April 2009, people with long-term conditions could expect local services to be provided by their primary care trusts (PCTs) and local authorities, if they were not already available. As a minimum, patients have a right to receive the right information when they want it, support with making small lifestyle changes, access to structured courses designed to provide the skills to self-manage, the opportunity to talk to other people about their condition

TABLE 1

The four pillars of Department of Health policy

Policy	Explanation
1. Information: more informed patients are more empowered people.	Information to support self-management should be at the centre of the choices offered to people with long-term conditions. This can include advice on how best to access health and social care services as well as broader advice on voluntary services, housing and education. By directing people to the right information about their conditions, and providing them with the confidence to use this information, people can gain more control of their illness and thus feel more empowered to live independently.
2. Skills and training: helping people to take care of their condition better.	Healthcare professionals, especially nurses, have a pivotal role in teaching people the skills to take control of their long-term conditions. This can be done by encouraging people to attend training courses.
3. Tools and devices: helping people to monitor their condition and control their medications.	Healthcare professionals have a duty to be aware of the tools and devices, both technological and non-technological, which can be used to self-manage long-term conditions. With the appropriate support, these interventions can have a significant effect on a person's quality of life and ability to live independently with such illnesses.
4. Support networks: boosting confidence and getting involved in the community.	Involving people with long-term conditions in their needs assessment and care planning is one of the most important ways in which health and social care services can be transformed into integrated services with the individual or his or her carer at the centre of the care plan. Directing people to relevant support groups could make the difference between someone living independently with a condition, or just living with it.

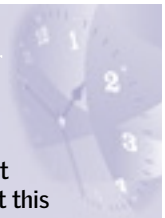
(DH 2009b)

and access to self-management aids for daily living or to improve their functional ability at home. This is not a new policy, but provides an opportunity to draw together all of the resources that are already available. It is applicable to all long-term conditions, which cover the four pillars of existing DH policy on support for self-management (Table 1).

These pillars complement the desires of people living with long-term conditions, since research has demonstrated that these patients would like to be more involved in their health care. Studies by the National Asthma Campaign have demonstrated that people with asthma desire more information about the condition, more involvement in treatment decisions and greater control of their own condition (Gibson *et al* 2003). Studies with people with cancer have also shown similar findings (Davies and Thomas 2007, Davies *et al* 2008).

An observation often made by doctors, nurses and other health professionals who undertake long-term follow-up and care of people with long-term conditions, is that the patient understands the disease better than they do (DH 2001). This knowledge and experience held by the patient has been referred to as an untapped resource that could benefit greatly the quality of patient care and ultimately the individual's quality of life (DH 2001).

Time out 4



Identify a patient with a long-term condition from your past or present practice. What condition does he or she have? List everything you have learned about this illness that you had previously been unaware of. This can include issues surrounding daily living as well as specific medical care. Highlight those aspects that were learned from the patient and identify what was important from the patient's perspective. Did the patient's priorities reflect your own clinical assessment of the patient's needs? Share this reflection with one or more of your colleagues, encouraging them to think about their own learning experiences.

Established user-led self-management programmes

Along with existing policy and patient desire to be involved in personal health care, there has been a rise in the number of self-management programmes available. These programmes can take a variety of approaches, but are primarily user-led. One of the leading authorities in this field is Professor Kate Lorig of Stanford University in the United States, who developed a community-based generic self-management programme know as the chronic disease

self-management programme. This is the most widely accepted self-management patient education programme worldwide.

The programme is popular mainly because of its generic design in meeting the needs of patients with all types of long-term conditions as well as multiple conditions (Lorig *et al* 1999). Several assumptions make this programme suitable for different long-term conditions (Box 1).

The content and process of teaching the chronic disease self-management programme are based on self-efficacy theory, people's belief in their ability to perform specific behaviours, which is a key factor to behaviour change and health functioning (O'Leary 1985). The chronic disease self-management programme incorporates strategies suggested by Bandura (1986) to enhance self-efficacy and includes (Lorig *et al* 1999):

- Weekly action planning and feedback.
- Modelling of self-management behaviours by participants for one another.
- Reinterpretation of symptoms.
- Education about different management techniques.
- Group problem solving and individual decision making .

Topics covered include exercise, cognitive symptom management techniques, nutrition, fatigue and sleep management. It also highlights the use of community resources, self-medication, dealing with emotions such as fear, anger and depression, and communication with others including health professionals.

BOX 1

Assumptions of the chronic disease self-management programme

- Similar problems and concerns are experienced by all people living with long-term conditions.
- People with long-term conditions can learn to take responsibility for the daily management of their conditions and any subsequent physical and emotional problems.
- Lay people with long-term conditions can teach the chronic disease self-management programme as effectively, if not more effectively, than health professionals.
- The process or way the programme is taught is as important, if not more important, than the subject matter taught.

(Lorig *et al* 1996)

In a five-year research project, the chronic disease self-management programme was evaluated in a randomised study involving more than 1,000 participants. This study found that people who used the programme, compared with those who did not, improved their healthy behaviours, for example exercise, cognitive symptom management, coping and communications with physicians, improved their health status, such as self-reported health, fatigue, disability, social activities and health distress, and decreased their time spent in hospital (British Liver Trust 1999).

Based on this approach and success of the initiative, the UK-based expert patient programme (EPP) was founded in 2001 (DH 2001). The EPP is a lay-led self-management programme, which aims to improve quality of life by developing the confidence and motivation of people to use their own skills and knowledge to take effective control over living with a long-term condition. The programme is based on the assumptions that people with long-term conditions need to:

- Know how to recognise and act on symptoms.
- Make effective use of medications and treatments available.
- Understand the implications of professional advice.
- Access social and other services (including transport).
- Manage work and access the resources of the employment services.
- Access chosen leisure activities.
- Develop strategies to deal with the psychological effect of illness.

As with the chronic disease self-management programme, those who have participated in the EPP have reported improved health, better coping with fatigue, less limitations in their activities of daily living and less dependency on hospital care (Richardson *et al* 2008). After successful piloting, approximately 12,000 EPP course places are available per year, and these places are now being made available through PCTs.

The effectiveness of lay-led self-management programmes in improving patient outcomes is outlined in Table 2 and improvements in health service use are outlined in Table 3.

The nurse's role in self-management

While self-management is fundamentally a personal and independent journey, interactions between healthcare professionals and the 'expert patient' are critical for the exchange of information and decision making. The Health Foundation uses

TABLE 2

Self-management programme outcomes

Programme	Outcome
Challenging arthritis is a user-led programme developed by Arthritis Care (2009) in which all senior staff, self-management trainers and volunteer course leaders have arthritis.	In randomised controlled trials consistent improvements in knowledge, self-efficacy and the use of self-management behaviours have been reported (Barlow *et al* 1999). Other arthritis programmes have reported reductions in symptom severity, especially pain (Barlow *et al* 1999).
The self-management training programme developed by the MDF The Bipolar Organisation (formerly the Manic Depression Fellowship) (2009) has been designed to enable individuals with a diagnosis of bipolar disorder to gain confidence in taking control of their lives.	Improvements in mood sustained three to six months after completion of the course have been reported (Department of Health 2001).
Self-management in multiple sclerosis (MS) has been developed by the MS Society (2009), and all tutors have MS.	In 2009, the MS Society began to train tutors to deliver structured self-management courses based on the Lorig *et al* (1999) model. Outcomes are still to be measured.
Asthma self-management (Asthma UK 2009).	Programme outcomes include reduced symptom severity (Allen *et al* 1995) and reduced quantity of medication used (Gillies *et al* 1996).
Generic self-management programmes for people with any chronic illnesses (Expert Patients Programme 2009).	Programme outcomes include reduced symptom severity (Horan *et al* 1990, Coleman *et al* 1999) and improved social function (LeFort *et al* 1998).

the term 'co-creating health' to describe an active and collaborative partnership between patients and health professionals (Coulter and Ellins 2006). For guided self-management to be successful, a positive patient-professional relationship has been shown to be a key factor (Coulter 1997, Clark and Gong 2000, Holman and Lorig 2000). It has been reported to enhance patient motivation (Hibbard and Cunningham 2008) and increase self-efficacy (Cimprich *et al* 2005), both of which are implicated in self-management.

Self-management programmes for people with long-term conditions not only offer benefits to the patient and the healthcare service, but also to individual healthcare workers. Family doctors, practice nurses and other primary and community clinicians will have greater opportunities and incentives to advise people on the measures they can take to improve their health.

Nurses, in particular, are at the forefront of a national shift towards self-management promotion. Indeed, specialist nurses are shown to provide efficient and cost-effective advice and care for people with progressive conditions such as multiple sclerosis and Parkinson's disease (Freeman and Thompson 2000, Evans *et al* 2002). Furthermore, several initiatives highlight the contribution of nurses to support the delivery of the National Service Framework for people living with long-term conditions (DH 2005) (Box 2).

The vast array of clinical and interpersonal skills held by nurses is particularly pertinent in meeting the self-management needs of individuals with complex problems arising from three or more long-term conditions. Nurses who work in this area of self-management promotion are known as community matrons, their primary role being to work with patients to assess their personal and support needs. Acting as a fixed point of contact for the patient, self-management becomes feasible by nurses overseeing and co-ordinating particular care needs while also acting as an educator and model to the patient. Not only does this approach to community nursing reduce hospital admissions, but it also complements the preference to remain at home which is felt by the majority of patients. Where possible, patients are able to choose where and when they receive care, including telephone contact, digital television, telecare and the internet.

Personalised care planning is an effective approach that nurses can use to identify the self-management needs of patients, as well as the level of support required by health professionals.

Time out 5

- Identify any generic and condition-specific self-management groups available in your local area.
- Place a list of these groups on a staff noticeboard or other visible location within your practice.
- Ensure these lists are regularly updated.
- Make a conscious effort to inform one or more patients of a relevant self-management group available to them in their local area.

Personalised care planning

Personalised care planning has become increasingly critical to effective self-management partnerships between healthcare providers and people with long-term conditions. Personalised care plans have been created to ensure that people with long-term conditions receive more individualised care and services to help them manage their conditions better and achieve the outcomes they want for themselves. In *High Quality Care for All* (DH 2008b) a promise was made that 'Over the next two years, every one of the 15 million people with one or more long-term conditions should be offered a personalised care plan, developed, agreed and regularly reviewed with a named lead professional from among the team of staff who help manage their care.' *Supporting People with Long Term Conditions* (DH 2009b) was developed to ensure that this vision for the use of personalised care plans becomes more widespread.

It is envisaged that care planning will take place mainly in primary and community care and will involve staff such as GPs, practice nurses, community matrons, allied health professionals and social care workers. It may also take place in secondary care and involve specialist staff such as specialist nurses or consultants. It has been emphasised within the *Supporting People with Long Term Conditions* (DH 2009b) guidance that all NHS staff need to be aware of personalised care planning and their role in delivering these plans.

Personalised and integrated care planning is essentially about addressing individuals' full range of needs, taking into account their health, personal, family, social, economic, educational, mental health, ethnic and cultural background, and circumstances. It is a holistic approach recognising that there are other issues in addition to medical needs that can affect a person's overall health and wellbeing. Providing people with quality, timely and relevant information is crucial, as is self-management advice. Risk management and crisis and contingency planning are central to the process. The key elements of personalised care planning are outlined in Box 3.

TABLE 3

Improvements in service use

Long-term condition	Outcome
Chronic pain Arthritis	Up to 80% reduction in the number of visits to health professionals (Cole 1998, Barlow *et al* 1999)
Arthritis Insomnia Asthma	Up to 44% reduction in the number of GP visits (Lorig and Holman 1989, Charlton *et al* 1990, Lorig *et al* 1993, Fries *et al* 1997, Oosterhuis and Klip 1997)
Sickle cell disease Asthma	Reduction in the number of hospitalisations (up to 31%) and length of stay (up to 50%) (Thomas *et al* 1984, Choy *et al* 1999)
Insomnia	Reduction in the number of visits to specialists by 15% (Oosterhuis and Klip 1997)
Sickle cell disease Asthma	Up to 39% reduction in the number of emergency department visits (Thomas *et al* 1984, Choy *et al* 1999).

BOX 2

Nurse delivery of the National Service Framework for people living with long-term conditions

- *Making a Difference: Strengthening the Nursing, Midwifery and Health Visiting Contribution to Health and Healthcare* (DH 1999) highlights the positive contributions nurses make to improving people's lives.
- *The NHS Plan: A Plan for Investment, A Plan for Reform* (DH 2000) requires NHS employers to empower appropriately qualified nurses, midwives and therapists to undertake a wider range of clinical tasks that enable self-management.
- *Liberating the Talents Helping Primary Care Trusts and Nurses to Deliver the NHS Plan* (DH 2002) describes continuing care, rehabilitation, managing long-term conditions and delivering the National Service Frameworks as core functions for all nurses in primary and community care.
- *The NHS Improvement Plan: Putting People at the Heart of Public Services* (DH 2004) identifies community matrons as key to delivering the targets for long-term conditions using case management techniques for planning and co-ordinating care.
- *Improving Patients' Access to Medicines: A Guide to Implementing Nurse and Pharmacist Independent Prescribing within the NHS in England* (DH 2006) discusses nurse prescribing including independent prescribing.

Time out 6

List the potential benefits of personalised care planning for:

- People living with long-term conditions.
- Carers of people with long-term conditions.
- The healthcare workforce, particularly nurses.

Share your thoughts and ideas with colleagues. Can they make any additions to your lists?

Conclusion

The personal and economic burden of living with a long-term condition is vast. The ageing

population and subsequent increase in the number of people living with one or more long-term conditions exacerbate this burden. Government initiatives are in place to enhance the quality of life of people with long-term conditions by developing skills and confidence to self-manage such illnesses. Nurses have a central role in caring for people with long-term conditions, as well as educating and promoting self-management practices. Although nurses have always contributed to self-management awareness, their role has become more explicit and the opportunities to use a vast array of clinical and interpersonal skills are at the forefront of this NS

Time out 7

Now you have completed this article you might like to write a practice profile. Guidelines to help you are on page 60.

BOX 3

Key elements of personalised care planning

- Place the individual, his or her needs and health choices at the centre of health care.
- Focus on setting goals and outcomes that people want to achieve.
- Take into consideration the needs of carers.
- Offer anticipatory and proactive health care via contingency (or emergency) self-management during crisis episodes.
- Promote choice and control by putting the person at the centre of the process and enabling better management of risk.
- Ensure that people with long-term conditions receive co-ordinated care packages.
- Provide information that is relevant and timely.
- Provide self-management support to prevent deterioration.
- Support multidisciplinary working between health professions and agencies.
- Conclude with a single care plan that is owned by the person, but can be accessed by those providing direct care and/or services, enhancing patient-provider partnership.

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