Self-management education in multiple sclerosis services

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This article discusses the benefit of providing good information and support networks for patients with multiple sclerosis. It reports the results of an audit examining the effectiveness of information programmes provided by MS specialist nurses and identifies patients’ views on services promoting self-management. It demonstrates the advantages of such initiatives, emphasising their role in empowering patients, and could be used by nurses working with patients with other chronic conditions.

National Institute for Clinical Excellence guidelines on the management of people with multiple sclerosis (MS) in primary and secondary care (NICE, 2003) recommend involving service users in structuring services. The nurse-led MS service at University Hospital of North Staffordshire has encouraged service users to become involved in shaping services since 1998 through a partnership focus group that meets regularly and involves people with MS, carers and professionals working with them.

Background

In 1998 an audit revealed that information provision at, and following, diagnosis was poor. Many nurse-led initiatives have since been developed to address this situation by empowering patients and improving services. In collaboration with three local MS Society branches, an education programme for newly diagnosed patients was initiated. The MS Society agreed to fund courses locally.

The MS Society and MS research Trust (1999), the RCN UK MS Specialist Nurse Association (2001) and NICE (2003) have developed best practice guidelines, which address situations where services are underdeveloped and poorly resourced. As the number of MS specialist nurses and therapists, and the provision of disease-modifying therapies increase (DoH, 2002) MS services are gradually improving.

Specialist nurses have been promoting best practice by encouraging self-management and positive attitudes and helping patients to feel more in control of the management of their condition. In North Staffordshire, an education programme is offered to patients soon after diagnosis (Box 1). This is followed by symptom management programmes to encourage patients to keep updating their knowledge about MS and to network with others experiencing similar issues.

Patients need high-quality information and support following a diagnosis of MS. This means they must have access to evidence-based information to enable them to make informed decisions about their care (Shepperd et al, 1999). Facilitating this is a crucial element of the nurse’s role in the long-term management of MS and other chronic conditions. A coordinated approach to informing patients following diagnosis is central to evidence-based care (Freeman et al, 1997; RCN, 2001; MS Society, 1998; 1999).

The literature

A literature search was undertaken on the provision of MS programmes and evidence of their value to patients. In a randomised-controlled trial assessing the effectiveness of arthritis self-management programmes, Barlow et al (2000) used quality-of-life measures. The group given information was found to have improved perceptions of control, health behaviour and health status and its members were significantly less depressed than the group given no information. The authors suggest the programmes also had a positive effect on fatigue, anxiety and pain management. Their findings imply that education programmes can encourage people to self-manage their disease, effectively promoting an improvement in their condition.

Some studies highlight the benefit of group support, which helps overcome any sense of isolation by helping patients to recognise that others have experienced similar issues to them and to identify alternative coping strategies (Schwartz, 1999; Stuibergen and Rogers, 1997; Barlow et al, 2000).

Health education and promotion programmes have also been shown to promote positive lifestyle changes and minimise complications by enabling people to manage their condition (Stuibergen et al, 2000). Improving the availability of information also helps to reduce anxiety, while behaviour can be modified and individuals can become empowered through improved well-being and autonomy (Hanger and Wilkinson, 2001).
According to Halper (2001) the nurse’s role should be supportive, while encouraging patients to take control of and responsibility for their own health and management of their condition.

In summary, the literature supports the hypothesis that people with chronic disease should have access to quality information at diagnosis and throughout the disease trajectory. This gives them greater control over their own health.

The programmes
The programmes offered at North Staffordshire are based on an adaptation of two models developed for people with newly diagnosed MS. Getting to grips with MS was designed by the MS Society and Taking Control by a group of specialist nurses (Brenchin et al, 2001).

They can be run as five weekly two-hour sessions in the evening or two four-hour afternoon sessions on consecutive weeks (Box 1). Patients are usually invited to participate after their initial consultation with the specialist nurse. The majority do so approximately six months after diagnosis.

In 1998, prior to the development of the MS specialist nursing service, an audit demonstrated that 43 per cent of patients found the information and support received at diagnosis inadequate and haphazard. A subsequent audit of existing educational programmes showed a significant improvement in the information provided to newly diagnosed patients.

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programmes was undertaken to explore the benefits people with MS felt following participation in a self-management programme. The aim was to:
- Provide an accurate, unbiased view of whether their information needs were being met;
- Examine what sources of information they found most useful;
- Explore whether health education encouraged them to adopt a healthier lifestyle.

The audit also provided useful information to other health professionals caring for people who are newly diagnosed with MS or other chronic conditions. It is recognised that a more in-depth analysis might be required in future.

The audit
A questionnaire was designed to elicit attitudes, views and beliefs held about information provision following diagnosis of MS. This was mailed to 103 patients who had participated in the self-management programmes in the previous two years. The questionnaire included open and closed questions to elicit information and Likert scales to measure their attitudes.

The response rate was 66 per cent, of which 38 per cent were male and 62 per cent female. The majority of respondents said the programme was timed appropriately and 94 per cent found it useful.

The MS specialist nurse was identified as the most useful source of information, with 70 per cent indicating the information received from the nurse was excellent. All health professionals were scored from 1 (excellent) to 5 (unsatisfactory); 28 per cent found information from their GP unsatisfactory and 79 per cent said that information from the MS Society was excellent or very good.

The following comments indicate the most common themes arising, which reflect respondents’ thoughts about the educational programme:
- It gave individuals a better understanding of their disease and its management;
- It helped to boost confidence and self-esteem following diagnosis;
- It reduced fears and dispelled myths about MS;
- It helped respondents to recognise they were not isolated;
- It helped them to identify support networks;
- It helped them to develop new friendships and a social network;
- Meeting other people with MS gave them access to useful advice based on personal experience.

Respondents identified that groups led by a professional provided the most useful information and 89 per cent found a combination of verbal, written, video material and discussion useful. Sixty one per cent of respondents said the programme met most of their needs. However 94 per cent believed annual update sessions would be useful.

This suggestion has since been acted upon.

Likert scales were used to assess attitudes, changes in behaviour and views as a result of the programme. The following summarises responses that strongly agree or agree with the comments:
- 82 per cent felt the programme had enabled them to cope better;
- 64 per cent ate a healthier diet thanks to the programme;
- 74 per cent said it had helped them and their families to adapt to living with MS;
- 53 per cent learnt how to manage fatigue more effectively;
- 60 per cent said that the programme had empowered them;
- 72 per cent were enabled to alter their lifestyle in a positive way.

Discussion
The literature review and evidence from the audit indicate that education programmes are valuable to patients and demonstrate that MS specialist nurses should continue to provide and develop them. They also demonstrate that nurses need to focus on positive health practices and attitudes. Further studies are required.

In areas where self-management education is not available, health professionals should be encouraged to explore the possibility of such programmes and to recognise the valuable contribution they make to people learning to cope with a chronic condition. Helping people to make positive adjustments to their lives and lifestyles ultimately enables them and their families to adapt to living with their condition.

The results indicate that educational programmes help people with chronic conditions to regain their confidence. They also help them to identify coping mechanisms and allow them to make positive changes that enable them to deal with a difficult and unpredictable condition.

The audit identified that MS self-management programmes should focus on:
- Useful coping strategies;
- Reducing isolation and stress;
- Identifying a social support network;
- Promoting positive health practices;
- Allowing individuals to take control of their own health care needs.

The mutual benefit and support the programme provides not just for people with MS but also for partners and other family members has been the ultimate benefit in helping them to self-manage their condition. Further work is being undertaken in North Staffordshire to determine the effects of ‘expert patient’ programmes (DoH, 2001) for people with MS. A concept analysis of self-management in chronic disease is also under way.