

The Multiple Sclerosis Partnership Programme by Rosie Wilson

Although scientific and clinical research has shown us that there are classic signs and symptoms of multiple sclerosis (MS), for each person with MS, the condition is a unique experience. The unpredictable acute and chronic clinical manifestations of MS produce symptoms laden with meaning for the individual. These meanings are often coloured by where the illness has interrupted their life course and by how MS is interpreted in their society.

Therefore, the need for professional health support runs on a continuum, from early presentation when diagnosis is established, to the management of an altered lifestyle when symptoms of MS begin to impose limitations. Nurses specialising in MS are now seeking to improve and individualise the clinical management of people with MS. Understanding how an individual's experiences influence and motivate them is central to MS nursing, as is the core for establishing a personalised plan of support which often extends to other family members.

Within the UK, the MS nurse has now evolved to provide a valuable resource to patients, their families and the healthcare team. A state-funded National Health Service (NHS) operates across the UK and a network of general practitioners (GPs) provides family care and refers people on for specialist treatment when necessary. General practitioners work with other health professionals including community nurses, neurologists and (where they exist) specialist nurses to offer all patients with MS a framework of support. Some neurologists employ their own MS specialist nurses; others are provided via sponsorship programmes including the Multiple Sclerosis Partnership Programme (MSPP).

The MS nurse in the UK usually works with patients in the community and in hospital-based clinics. For the patient, the service is enriched by home visits, which allow the MS nurse to make a holistic assessment of their situation. Patients have also reported that it is easier to talk to nurses in their own homes, especially in relation to difficulties with elimination and sexual dysfunction.

A specialist MS nursing service helps to make neurological care more efficient because patient/carer contact with the nurse is often direct, and avoids additional consultations. GPs have also found that using the services of an MS specialist nurse can reduce their workload and enhance their knowledge of MS. The MS nurse can act as a valuable 'fast track' link between the neurologist and the patient if a case review is necessary, which can lead to a reduction in follow-up appointment time and hasten emergency referral.

The MS Partnership Programme (MSPP)

The MS Partnership Programme was established in 1995, at a time when interferon therapy was about to become available to neurologists in the UK and the need for a widespread specialist MS nursing service across the UK was recognised. When interferon beta-1b was first licensed in the USA in 1993, it soon became clear that patients receiving treatment needed considerable professional support. The technique of self-injection needed to be taught and monitored, and patients who were considered to be unsuitable for treatment needed appropriate counselling.

Although the MS nurse has a valuable role, there are considerable costs involved with every person employed, including salary, communication, information technology, transport expenses, and ongoing training. The NHS is government funded and expenditure is, therefore, strictly controlled. Consequently, very few neurological clinics have the funding available to employ MS nurse specialists. Through the introduction of MSPP sponsored nurses, NHS hospitals are being offered a specialist resource with all salary and expenses paid.

The introduction of sponsored nurses, however, has raised concerns within nursing in the UK. Some feel that sponsorship may reduce choice; there is a risk that such nurses may demonstrate bias toward the products and services of one pharmaceutical company¹. Such concerns, however, are not founded with the MSPP, because the initiative is a partnership jointly developed by Schering Healthcare Ltd and Innovex UK Ltd, the latter being an internationally recognised service organisation that runs a variety of specialist nursing programmes. Innovex UK Ltd is able to alleviate the element of bias because training is organised independently from the pharmaceutical sponsor and it recruits, employs, trains and manages the MS nurses through a nurse-led structure. Employment through Innovex Ltd ensures that MSPP nurses work within the code of practice stipulated by the United Kingdom Central Council (UKCC) for Nursing. Innovex UK Ltd also facilitates an objective review process for the MSPP, through a steering committee established in conjunction with the Royal College of Nursing. The committee undertakes ongoing audits, using feedback from both neurologists and patients. The MSPP also works in line with the Association of British Neurologists, and national and local branches of the MS Society.

Assessing the nurse's value

After 1 year an audit was undertaken to assess the patients perceptions of this service. Following discussions with neurologists and Kirker et al.2 who had evaluated the MS nurse, an anonymous questionnaire was developed and mailed to a random sample of 50 patients in each region (total 100 patients).

Overall, the responses scored between 89–100% satisfaction. The scores were higher than anticipated and this could have been a reflection of the paucity of support available prior to the employment of the MSPP nurse in this region. The value placed on both home visits and the extension of support to the patients' families and friends scored particularly highly.

The reported reduction in patient visits to the GP (79–84%) was higher than that found by Kirker et al.2, where a quarter of patients contacted their doctors less often and GPs reported a 'reduced workload in caring for one third' of MS patients with the support of the MS nurse. This variable is interesting, but not significant due to the subjectivity of the audit.

Regarding the qualitative responses the most common issues raised were the value of the link provided by the MS specialist nurse, and the patient's desire for more follow-up. As a result the service was reviewed and reorganised to allow nurses more time with patients, and nurse-led clinics were introduced. There are three nurse-led clinics in different hospitals each week. These clinics are entirely managed by the nurse and are held in hospital outpatient departments, so that a neurologist is close by for advice if necessary. Clinic time is spent either assessing new patients, planning strategies of support, imparting health promotion and condition-related information on MS, counselling patients and their families, and following-up or reviewing presentations of symptoms. The nurse clinic enables a less hurried and more detailed patient interview, often lasting an hour. They enable more patient contacts within a day by reducing travelling time and have been acknowledged as increasing quality of care.

Conclusion

People with MS who receive care and support from nurses funded through the MSPP have reported an improved level of communication. They have a greater understanding of what to expect from their condition, and they value the link that the MS nurse provides between the patient and neurologist highly.

To conclude, an example of the value an MS nurse provides can be seen in a situation recently facing the author, when a new female patient visited her clinic. Although the patient has had MS for 5 years and was fully ambulant, she relayed her experiences of a number of different, invisible symptoms such as diplopia, blurred vision when tired, fatigue and sensory symptoms. To the MS nurse this history was quite typical and suggestive of a mild prognosis. The patient's interpretation was quite different, and she was very frightened. After listening to the author's interpretation of her experiences and offers of support and information, she was visibly reassured. At the end of the interview the patient said: 'To have a person that you can talk to and build a rapport with, a professional you can chat to like a friend, that's what I needed.'

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References

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