



# IOMSN Update

## Multiple Sclerosis Nursing in 2002: A Global Perspective

### Document Defines Role of MS Nurses in the UK

On April 25, 2001, during MS Awareness Week, a set of guidelines entitled “Specialist Nursing in MS—the Way Forward: key elements for developing MS specialist nurse services in the UK”

was released. The goal of the project, which was sponsored by an unrestricted grant from major pharmaceutical companies, was to describe, define, and develop MS-specialist nurse services in the United Kingdom.

The report describes the role of the MS nurse, identifies the resources required to initiate such a position, assesses cost implications, determines development require-

ments, considers different models of care, and sets standards of clinical operation. The hope is that the project will improve care for persons with MS in the United Kingdom both by raising awareness about MS nurses’ responsibilities and by increasing the number of MS nurses. The document is available on the Internet at the MS Research Trust Web site ([www.msresearchtrust.org.uk](http://www.msresearchtrust.org.uk)). **MSX**

### MS Nurses Are Integral to Managing Severe Spasticity

According to L. Jarrett, a Spasticity Management Clinical Nurse Specialist, MS nurses play an integral part in the management of severe spasticity in people with MS. Intrathecal baclofen therapy (ITB) is one method that nurses use to manage severe lower limb spasticity. The author outlined some of the responsibilities that MS nurses have when implementing and maintaining ITB therapy.

For ITB to be successful, it requires the completion of many stages, including spasticity assessment, an ITB trial, pump implantation, discharge planning, a 24-hour help line, ongoing pump refills, and dose titration clinics; MS nurses play a unique and an important role during each step. Further, MS nurses are involved with minimizing sensory stimuli to reduce flexor spasms, maximizing postures in lying and

sitting to promote comfort and reduce pain, providing drug education, and determining whether spasticity is having an impact on the person’s sexual functioning and/or emotional well-being.

Maintaining an ongoing relationship with the patient allows the nurse to offer advice, support, and referrals to other specialists.

Maintaining an ongoing relationship with the patient allows the nurse to offer advice, support, and referrals to other specialists. The continuation of self-directed ITB learning programs will ensure that MS nurses are qualified to manage this therapy for people with MS. **MSX**

## What Affects Quality of Life in Persons With MS?

Marital status and income do not appear to have a significant impact on quality of life for persons with MS, according to a German study conducted by researchers from the University of Hamburg, Germany. In a survey that combined the Hamburg Quality of Life Questionnaire in Multiple Sclerosis with inquiries regarding various sociodemographic factors, marital status and income were not major in-

fluences on quality of life in this German population.

The researchers, led by Heesen and colleagues, received 434 replies from persons with MS (70% women, mean age: 44, mean disease course: 10 years). While 22% of the respondents lived alone, their answers indicated no differences in quality of life when compared with the replies from persons with families or from those living as part of a couple. Results did show that quality-of-life scores were significantly higher for women than for men. Also, participants with more education (13 years of school or more) tended to rate their quality

of life as better than did those with less education.

It should be noted that quality of life was found to be significantly greater for those with MS who were employed. However, 27% were paying rent of less than 750 Eurodollars per month, which suggested that these respondents had a lower income level, yet there was no consistent corresponding drop in quality-of-life scores.

Based on all of the study data collected, the authors concluded that marital status and income seemed to have only a minor influence on quality of life for those with MS. MSX

## When Standard Treatment Is Not Enough

A poster presented by Jeannine Christopherson, RN, BScN, at the MS International Federation International Conference 2001 in Australia last September outlined a challenging case study. It involved a 40-year-old man with progressive-relapsing disease whose condition was being managed by an MS clinic nurse in Edmonton, Alberta, Canada. His Expanded Disability Status Scale score was 6.5 and his symptoms included spasticity, neuralgic pain, neurogenic bladder and bowel, and depression. He was married with children and employed full time.

Both interferon treatment (six months) and mitoxantrone therapy

(11 months) needed to be discontinued because of a significant drop in platelets. While he required narcotics to control pain, the side effects caused constipation. As his disease progressed, his despondency increased. Because the prescribed antidepressants lowered his libido, this individual chose not to adhere to regular treatment although he did take them intermittently for four years. He also refused to attend personal and family counseling, which were recommended because of the many difficulties that he faced in his day-to-day life.

Despite his continued despondency, he remained in close contact with his clinic nurse. They met three times per year and spoke at least once a week. The nurse experienced much frustration and mixed emotions since drug treatment could not be con-

tinued and because the patient refused formal counseling. In this particular case, the nurse was able only to provide emotional support through listening and to guide the patient with his medication regimen. In doing so, the nurse remained objective and supported the patient's decisions, even though they were contrary to the nurse's recommendations.

Over a three-year period, the person with MS gradually improved his ability to cope as observed by fewer telephone calls to the nurse and as noticed by an elevation in mood and a lessening of despair during the contacts that did occur. While the search for viable treatment in this case is ongoing, the continual contact with the nurse who provided a caring ear appears to have alleviated some of his frustration. MSX

## The Nurse Consultant: A Pivotal Player in MS Care

The recent advances in MS drug therapies coupled with the variable course of this disorder are shaping the role of the MS nurse consultant in Australia. A clinical update that appeared in the September 2001 issue of the *Australian Nursing Journal* outlined the challenges facing these care providers.

The authors described the general functions of the MS nurse consultant as: being pivotal in initiating and maintaining immunotherapy for the person with MS, both in the hospital and in the community setting; assisting in coordinating drug and other related trials; and providing education in the administration and maintenance of drug therapy. In caring for a person with MS, today's nurses must consider not only the disease symptoms, but also the emotional and psychological implications of a disorder whose manifestations are random and unpredictable and whose prognosis may vary from slight ailment to severe disability.

Specifics of the nurse consultant role were discussed within the context of a three-pronged approach to MS disease management: symptom control; disease-modifying therapies; and acute-relapse treatment. For

symptom control, the nurse needs to be aware that addressing one symptom may adversely affect another (eg, a drug that manages spasticity may exacerbate drowsiness and fatigue). Here, the nurse can help the person with MS to establish priorities for symptom relief and can provide guidance in preventative measures for symptom management.

Regarding disease-modifying therapies, the nurse consultant should emphasize that available medications are treatments, not cures, with the goals being to reduce the incidence of exacerbations and to delay, and not necessarily to prevent, increasing disability. The MS nurse needs to provide support and encouragement for the long-term use of these drugs, and offer strategies for dealing with side effects. When treating an acute relapse, the nurse needs to ensure that the individual with MS realizes that this medication has a limited purpose (ie, to shorten the relapse length) and will not change the progression of the disease.

The authors stressed the importance of being sensitive to MS issues and building a trusting relationship with the person having this disorder, so that ongoing assistance can be sustained as long as necessary. **MSX**

Coleman J, Rath L, Carey J. Multiple sclerosis and the role of the MS nurse consultant. *Aust Nurs J*. 2001.

## Long-Term Study of Abnormalities on MRI and Disability from Multiple Sclerosis

For many years, neurologists and those in related areas have used magnetic resonance imaging (MRI) scans of the brain to help in making the diagnosis of MS. Although no single test is definitive, the presence of such abnormalities as white-matter lesions in the cerebrum on MRI is linked with a greater risk of developing MS.

Now, however, a new long-term British study of the relation between such abnormalities on MRI and the extent of disability from MS further supports the idea of an association. The study, which appeared in a recent issue of *The New England Journal of Medicine*, was performed by researchers led by Dr.

Peter Brex at the Institute of Neurology in London. The principal goal of this study was to assess the strength of the relationship between volumes of lesions on previous MRI scans and the extent of disability after the passage of a number of years.

In a serial MRI study that used radio waves and magnetic fields to capture cross-sectional images of the brain, 71 individuals with isolated syndromes that suggested clinical MS were reevaluated after a mean of just over 14 years. Specifically, such isolated syndromes involve optic neuritis, the brain stem, or the spinal cord, and persons with them could develop MS at any point in time thereafter from months to many years. Kurtzke's Expanded Disability Status Scale (EDSS) was used to measure the level of disability.

Forty-four of 50 people (88%) with abnormal results on MRI at presentation and four of 21 individuals (19%) with normal results on MRI developed clinically definite MS.

In individuals who present with isolated syndromes that suggest MS, the increases in lesion volume on MRI of the brain in the first five years correlate with the extent of long-term disability resulting from MS. Because this relation is only moderate, the authors observed that the volume of the lesions alone may not be a sufficient basis for deciding whether to use disease-modifying treatment.

Some 98% of those with MRI abnormalities at baseline exhibited either clinical or radiologic evidence of multiphasic disease. It is thought that this long-term follow-up study confirms that white-matter lesions on MRI of the brain in young adults with isolated syndromes are due to MS in nearly all cases.

At 14 years, the EDSS score correlated significantly with volumes of lesions on MRI at all previous time points. The authors interpreted this as indicating that the volume of lesions at any time contributes to the development of later disability. Although numbers of lesions show broadly similar correlations, they are less reliable than volumes as a measure of disease progression. This is because such factors as enlargement and confluence of lesions cannot be accounted for and lesion sizes vary.

According to the authors, a relation between clinical features in the early years of MS and long-term disability has been identified by natural history studies.

In the first two to five years after the development of an isolated syndrome, both MRI and clinical measures of disease activity are important in the long-term prognosis for disability in persons with MS.

This is suggested by the MRI study under discussion as well as by previous clinical studies.

Aside from the total volume of the lesions, there are other pathologic features that are likely to con-

tribute to disability. Such features include spinal cord disease, axonal loss in lesions, abnormalities in the normal-appearing tissues, and diffuse atrophy.

tribute to disability. Such features include spinal cord disease, axonal loss in lesions, abnormalities in the normal-appearing tissues, and diffuse atrophy.

According to the authors, a relation between clinical features in the early years of MS and long-term disability has been identified by natural history studies.

tribute to disability. Such features include spinal cord disease, axonal loss in lesions, abnormalities in the normal-appearing tissues, and diffuse atrophy.

The current study demonstrates that lesion volume on MRI in individuals with isolated syndromes and early MS (which is defined as the first five years of the disease) is of prognostic value in evaluating the risk of future disability. The authors stressed that because the correlations are only moderate, lesion volume alone should not be used in deciding whether to employ disease-modifying treatments for affected individuals. The results do seem to suggest a potential long-term clinical benefit of treatments

that suppress the formation of lesions early in the course of the disease. However, the study authors caution that the mechanisms underlying the observed relation between clinical and MRI data are uncertain.

For this reason, they believe that there should be prospective long-term follow-up of individuals receiving disease-modifying treatments to shed further light on this issue.

MSX

Brex PA, Ciccarelli O, O'Riordan JI, et al. A longitudinal study of abnormalities on MRI and disability from multiple sclerosis. *N Engl J Med.* 2002;346:158-164.

INTERESTED IN SHARING  
YOUR KNOWLEDGE  
WITH THE WORLD?  
JOIN THE IOMSN!

The IOMSN is the only organization dedicated to the education of MS nurses around the world. If you wish to join the IOMSN, you can access it on the World Wide Web at [www.iomsn.org](http://www.iomsn.org), or contact the organization at:

**IOMSN**

c/o Bernard W. Gimbel MS Comprehensive Care Center

718 Teaneck Rd  
Teaneck, NJ 07666  
(201) 837-0727