



Multiple Sclerosis Nursing in 2005: A Global Perspective

IOMSN Announces New Mentorship Program

The IOMSN recently implemented a Nurse Mentorship Program. MS nurses who participate in this new program will have the opportunity to acquire the skills and knowledge needed to provide the highest quality of specialized MS nursing care and to become active participants in the MS clinical community, explained Colleen Harris, RN, NP, Chair of the Education Committee of the IOMSN.

The Nurse Mentorship Program is intended for nurses who are new to the field or who are planning to become involved in MS care. "This program will give nurses the opportunity to practice under the tutelage of an MS nursing expert," noted Ms. Harris. "It will also provide participants with a core curriculum of key peer-reviewed articles and references so they can update their theoretical knowledge of MS." After completing the program, apprentice nurses will be eligible for funding to cover the

registration fee for the MS Certified Nursing Exam.

Candidates must submit a detailed application form, along with a letter of recommendation, to the IOMSN. The application will then be reviewed by the Mentorship Committee.

"We will provide each candidate with a needs-assessment questionnaire outlining the various

explained Ms. Harris. At program completion, both the mentor and the apprentice will complete a formal evaluation of the experience. "While currently limited to the United States, it is anticipated that this program may become an international model," said Ms. Harris.

The IOMSN hopes to provide mentorship opportunities to ap-

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areas of MS nursing," said Ms. Harris. "Each participant can then decide in which area he or she would like to focus during the mentorship experience."

Once a nurse has been accepted into the program, the Mentorship Committee will match him or her with an appropriate mentor from the MS nursing community. The mentorship will last for two days and will ideally be completed in a continuous period,

proximately 50 nurses in the program's first year. Qualified nurses who are interested in becoming mentors for the program should contact the IOMSN by e-mail at info@iomsn.org. Candidates wishing to be matched with a mentor may obtain further information from the IOMSN Web site at www.iomsn.org. The application process is ongoing and candidates will be notified as soon as a decision is reached.

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Employment Issues in MS

Keeping MS Patients Working

Unemployment is an unfortunate, though common, reality following a diagnosis of MS. Although they are employed full time at the time of diagnosis, the majority of adults with MS become unemployed at some point after being told that they have the disease.¹ One study showed that loss of income due to unemployment may account for up to 75% of the total cost of MS.²

Workplace accommodations for individuals with disabilities have made it possible for many people with MS to continue working. However, many MS patients are not receiving appropriate vocational rehabilitation, according to Diane Playford, MD, FRCP, Senior Lecturer/Honorary Consultant Neurologist at the Institute of Neurology and the National Hospital for Neurology and Neurosurgery in London. During her talk on work retention in MS at the recent MS Trust meeting in Harrogate, United Kingdom, Dr. Playford stressed the importance of developing services that encourage MS patients to remain employed for as long as possible.

“Studies show that the high unemployment rates for individuals with MS are similar throughout the world,” said Dr. Playford, citing data from the United States, Canada, and Europe. “However, the same studies show that the level of disability of most of these patients is relatively low,” she added. “Many people with MS are leaving work when they’re still relatively mobile.” For example, in one study 77% of participants with MS were unemployed, even though most could walk independently.³

Improving Vocational Services for People With MS

Dr. Playford and colleagues surveyed MS patients to determine what employment advice they had received in the past and what kinds of vocational services they would be interested in receiving. “We asked 100 patients of all ages and with varying subtypes of MS,” Dr. Playford reported. “Of those we surveyed, only 20% had actually received any type of employment advice.” Most of the vocational advice had been obtained from a hospital occupational therapist (OT). “It was interesting to note,” said Dr. Playford, “that well over half of those surveyed said they wanted this advice but didn’t know where to obtain it. Yet, when we

developed such a service, we were unable to recruit enough patients.”

Based on the results of the survey, Dr. Playford and her colleagues came up with several suggestions to help improve vocational rehabilitation services for people with MS. “A vocational service should fit the needs of patients and provide them with the information and therapy they require,” she said. Programs should involve a multidisciplinary team, not just OTs. For example, MS nurses and other health care professionals can help to develop strategies for managing symptoms such as fatigue and incontinence, which may interfere with work. In addition, psychologists could help patients with cognitive problems involving memory and/or concentration. “These programs need to be well-funded in order to employ an appropriate staff,” she added.

Perhaps most importantly, people with MS need to be made aware that such a service exists. “As clinicians, we need to start querying our patients about their employment history and instructing them about where to go to receive help.

“It sounds obvious,” said Dr. Playford, “but a vocational program should be one that people actually want to attend. For instance, the language we use in vocational rehabilitation may be perceived as disparaging. We should avoid using terms like ‘work evaluation.’ Patients may hear those words and feel that their performance will be scrutinized and judged.”

Convenience and accessibility are also important issues, Dr. Playford stressed. “If someone is disabled, has a job, and/or has responsibilities at home, it may be difficult for that person to spend a day or a week at a hospital to attend a vocational rehabilitation program. We need to be flexible in the way we structure our programs.”

She pointed out that current vocational rehabilitation tends to focus on getting individuals who are disabled back to work. “However, this is not usually the main issue in the MS population; most patients are already employed at the time they are diagnosed,” she noted.

Shifting Attitudes

“Health care providers should be encouraged to join with occupational and vocational therapists to try to keep MS patients working for as long as possible,” she stressed. “In order to accomplish this, we first need to create a shift in health care workers’ attitudes.” For ex-

ample, she noted that many clinicians simply do not inquire about the work-related needs of their MS patients. “We audited the OT outpatients at our clinic and found that, while 18 of 20 had work-related needs, only two had been referred for those reasons.” The clinicians had either downplayed the significance of the issue or hadn’t realized it was a problem that should be addressed. “MS health care providers need to realize how important remaining at work is in many of their patients’ lives and encourage rather than discourage the continuation of employment,” she said.

“The rewards of continuing to work for people with MS can be much more than financial; employment can create a sense of purpose, personal fulfillment, and a feeling that one is contributing to society, which is especially important in light of the depression and despair that are so common in people with MS,” Dr. Playford pointed out. “Anyone who wishes to remain at work should have every opportunity to do so. Hopefully, we can make that a reality.”

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—Krista Binetti

REFERENCES

1. Roessler RT, Rumrill PD Jr. Multiple sclerosis and employment barriers: a systemic perspective on diagnosis and intervention. *Work*. 2003;21:17-23.
2. Battaglia MA, Zagami P, Uccelli MM. *J Neurovirol*. 2000;(6 suppl 2):S191-S193.
3. Larocca N, Kalb R, Scheinberg L, Kendall P. Factors associated with unemployment of patients with multiple sclerosis. *J Chronic Dis*. 1985;38:203-210.

Understanding and Managing Bowel Dysfunction in MS

Bowel dysfunction is especially common in diseases like MS that affect the nerves and muscles. In fact, up to 70% of individuals with MS report constipation and/or fecal incontinence.¹ Bowel complications can negatively affect everyday life, contributing to embarrassment, feelings of anxiety, and, often, an inability to work or to

engage in social activities. At the recent MS Trust conference in Harrogate, UK, Christine Norton, PhD, RN, discussed bowel dysfunction in MS and offered some insight on treating and managing this condition.

Professor Norton, a nurse consultant at St. Mark’s Hospital and Professor of Nursing at King’s College, both in London, pointed out that despite its high prevalence in the MS population, little is known about the impact of bowel dysfunction on those with the disease. “Of

18,000 articles on MS published in medical journals over the last 30 years, only 30 have focused on bowel dysfunction and not one was a treatment study,” Prof. Norton noted.

Symptoms related to the bladder and the bowel are rated by patients as the third most common factor limiting their ability to work (after spasticity and incoordination).¹ “Those with bowel problems obviously experience a reduced quality of life as well,” Prof. Norton said. “They may avoid places and activities where a rest room is not readily available.”

How MS Affects the Bowel

Prof. Norton discussed how the physical changes that occur in MS also may affect the bowel. “MS impacts the sensory and motor function of the anorectum,” she explained. “This contributes to reduced sensation. In effect, the call to have a bowel movement becomes blunted, leading to constipation. A host of other MS-related causes, such as slow colonic transit and failure of the puborectalis muscle to relax may also contribute to the condition.

“Conversely, the striated muscles of the external anal sphincter and pelvic floor may become weak or uncoordinated, so individuals may not be able to resist the urge to have a bowel movement.” All of this probably results from a combination of central nervous system lesions and autonomic dysfunction, she explained.

“While bowel disorders are associated with more severe disability and greater disease progression, they

are not associated with gender nor necessarily with bladder problems,” Prof. Norton added. These complications also do not appear to show specific patterns among the different subtypes of MS.

Determining the Cause

Prof. Norton cautioned clinicians against assuming that an individual is experiencing bowel dysfunction based on the presence of MS. “Childbirth or other anal sphincter trauma, rectal prolapse, and irritable bowel syndrome all may contribute to fecal incontinence, while constipation may be attributed to a host of other causes as well as to MS.”

To confirm that bowel-related symptoms are related to MS, “a comprehensive history of the patient should be taken and a complete physical examination should be performed,” Prof. Norton said. A colonoscopy also may be warranted, especially in the presence of a change in bowel habits or rectal bleeding.

Treating the Problem

Some nonpharmacologic methods may initially be helpful to patients with constipation, she suggested. “It is important to educate the patient about normal bowel activity,” she said. In addition, patients should be made aware of the importance of consuming adequate amounts of fiber and fluids. Those taking medications should be advised to review them with their clinician and to ask if it’s possible to change any medicine that may be causing constipation. As a last resort, she adds, low-dose laxatives or glycerin suppositories may be prescribed.

“As troubling as constipation may be,” Prof. Norton noted, “fecal incontinence can be much more distressing for individuals with MS, causing anxiety and limiting their ability to work and interact socially.” Prof. Norton said that treatment is mostly a trial-and-error process. “Pelvic floor exercises and vaginal electrical stimulation have been shown to help manage urinary incontinence but, as of yet, there is no evidence to recommend these treatments for fecal incontinence. Some options may include drugs such as

loperamide (Imodium®) and, in severe cases, surgical interventions, she said. In 2000, a study published in the *Journal of Neurology, Neurosurgery, and Psychiatry*² suggested that biofeedback may be effective for certain individuals with MS who also experience constipation and fecal incontinence. Of 13 MS patients who underwent the treatment, five showed a positive response. “However, a response was more likely for those patients who experienced limited disability and whose disease course was not progressive,” Prof. Norton added.

“There is an urgent need for greater public awareness of bowel dysfunction in individuals with MS,” Prof. Norton stressed. “People delay seeking treatment for these problems, perhaps due to a perceived lack of clinical services. Patients should be questioned by clinicians with regard to their bowel function, as they may be hesitant to bring up the issue themselves. Finally, we as clinicians should conduct further research into effective treatment options for this common and often debilitating condition.”

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REFERENCES

1. Wiesel PH, Norton C, Glickman S, Kamm MA. Pathophysiology and management of bowel dysfunction in multiple sclerosis. *Eur J Gastroenterol Hepatol.* 2001;13:441-448.
2. Wiesel PH, Norton C, Roy AJ, et al. Gut focused behavioural treatment (biofeedback) for constipation and faecal incontinence in multiple sclerosis. *J Neurol Neurosurg Psychiatry.* 2000;69:240-243.

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