



Multiple Sclerosis Nursing in 2002: A Global Perspective

Harrogate Conference Offers International Perspective on MS Nursing

Addressing an audience at the IOMSN meeting in Harrogate, United Kingdom, an MS patient commented that when looking back over the years, the most helpful service she could have received at the time of her diagnosis would have been the support of an MS nurse specialist.

This patient's belief in the MS nurse's role validated the purpose of a gathering such as the Harrogate conference, according to IOMSN president Kathleen Costello, RN, MS, CRNP. In her closing remarks, Ms. Costello reminded the attendees that despite international differences in health care systems, all MS nurses share a common ground in their varied roles as friend, educator, caregiver, and confidant to the MS patient.

The 250 conference attendees represented approximately 15 different countries, spanning from Eu-

rope all the way to Australia. "In any country, nursing is consistently about the relationship between the nurse and the patient," she noted. "The nurse must utilize his or her knowledge and skills to empower the patient to cope with a lifelong disease. MS is dynamic with physical, psychological, and economic challenges," she continued. "In any health care system, the nurse is strategically placed to coordinate the efforts necessary to meet these challenges."



Kathleen Costello, RN, MS, CRNP
IOMSN President

rope all the way to Australia. "In any country, nursing is consistently about the relationship between the nurse and the patient," she noted. "The nurse must utilize his or her knowledge and skills to empower the patient to cope with a lifelong disease. MS is dynamic with physical, psychological, and economic challenges," she continued. "In any health care system, the nurse is strategically placed to coordinate the efforts necessary to meet these challenges."

According to Ms. Costello, who assumed IOMSN presidency in 2002 and is based at the Maryland Center for Multiple Sclerosis in Baltimore, the meeting in Harrogate was organized in conjunction with the MS Trust meeting to provide IOMSN members with a worldwide perspective on MS nursing. Although the speakers identified regional and national differences in areas such as patient access to care, access to disease-modifying drugs, funding of MS programs, and the organizational role of the MS nurse specialist, Ms. Costello said she was struck more by the participants' similarities than by their differences.

"What impressed me most about this conference," she noted, "was the level of commitment and dedication of this group of professionals, despite the significant challenges involved in working with this disease."

Ms. Costello reminded the audience that the goals of the IOMSN are to facilitate the development of a specialized branch of MS nursing, to establish standards of nursing care in MS, to support ongoing nursing research, and to educate the health care community. The overriding goal is to improve care for people living with MS, she said. "These goals put us on a journey that will end only when MS either can be cured or completely controlled. Along the way, we will have successes as well as tragedies. We will learn from our patients, their families, and our colleagues. We will sustain each other with our ideas and our stories—our failures and our successes.

"The work that we do is very demanding, frustrating, and exhausting at times," she concluded. "Meeting together, learning, and laughing—maybe even raising our glasses—is good for us. The relationships I have formed with my MS colleagues are vital to my own sense of hope in this difficult role."

MSX

Pediatric MS Presents Unique Treatment Challenges

Until recently, it generally was believed that only adults developed MS. However, as the prevalence of the disease increases, it has become clear that children not only develop MS—approximately 5% of patients are diagnosed before the age of 18 and an age of onset as young as 10 months has been reported—but also that its incidence in children may be underestimated. Many people who were diagnosed with MS as adults report having experienced some symptoms when they were children. The potential for numerous differential diagnoses, as well as the hesitancy of some health care professionals to diagnose a child with a potentially disabling disease, may contribute to its underrecognition.

At the same time, the number of health care professionals with expertise in pediatric MS remains small. That may translate into challenges for patients and their families, as well as for those who treat young patients, said Jennifer Boyd, RN, MHSc, Clinical Nurse Specialist with The Hospital for Sick Children Paediatric Multiple Sclerosis Clinic in Toronto, Ontario.

Speaking at the November 2002 International Perspectives on Multiple Sclerosis conference in Harrogate, United Kingdom, Ms. Boyd stressed the importance of recognizing that children with MS “are not little adults.” Factors that may be unique to children should be considered carefully when devising a treatment and care plan.

“Health care providers need to adapt care and patient education based on developmental issues because children have different cognitive, physical, and emotional needs than do adults,” she said. Education regarding issues such as injections—a major challenge in treatment of young children—or energy conservation should be tailored to the child’s age and cognitive capacity.

The most effective way to educate parents may be to address key issues as though the parent, not the

child, has MS. “You need to provide the parents with information about MS and its treatment as you would a patient with MS, because they’re the ones making the treatment decisions,” noted Ms. Boyd.

Psychological and Learning Issues

Caregivers should recognize that the main concerns of children and adolescents with MS involve academic performance, peer relationships, and recreation or play, Ms. Boyd explained. “One of their biggest concerns relates to memory and concentration problems, which are very important when they’re in school,” she said. Young patients may need psychological support to address the effects of the illness on these kinds of activities. Health care providers also may want to assist in the process of informing teachers and school personnel about MS symptoms, children’s physical limitations, or possible cognitive issues, she added.

As young patients move into middle adolescence—a time when they typically attempt to exert their independence—treatment adherence may become a problem. At the Toronto clinic, which currently

has 31 patients (see table), refusal to adhere to treatment has been rare and tends to occur among patients in their mid-teens, said Ms. Boyd.

Factors that interfere with adherence include psychosocial issues such as concerns about physical appearance and differences from peers; acting out or risk-taking as “cop-

ing” mechanisms; a high degree of personal stress or conflict between the child and his or her parents; and a lack of support from peers or a perceived lack of respect from health care professionals. On the positive side, fully involving adolescents in making treatment decisions may improve adherence.

Children with MS should be actively encouraged to live as normally as possible. “Many of the kids [at the Toronto clinic] are not disabled on a day-to-day basis by their disease, so often they’re able to carry on fairly normal lives. It’s important to try to normalize the situation for them,” she suggested.

TORONTO CLINIC PEDIATRIC MS PATIENTS

| | |
|---------------------------------|--------------------------------|
| Clinically definite MS : | 31 patients |
| Gender: | 14 male, 17 female (1:1.2) |
| Ages: | 7–20 years (mean = 14.5 years) |
| Age ≤ 12 years: | 11 (35%) |
| Age of onset: | 4–17 years (mean = 11.0 years) |
| Presentation at age ≤ 10 years: | 15 (48%) |
| Disease duration: | < 1–8 years |

Treatment Implications

Although care of pediatric MS patients requires a particular set of skills and a modified approach, the disease's manifestation and treatment protocols are not markedly different for children than they are for adults. Children present with essentially the same symptoms but are more likely to be systemically ill at presentation—with malaise, irritability, low-grade fever, and other indications of encephalopathy—than are adults. Although retrospective studies indicate that

The potential for differential diagnoses, as well as the hesitancy of some health care providers to diagnose a child with a potentially disabling disease, may contribute to the underrecognition of MS in children.

53% to 65% of children have relapsing-remitting MS (RRMS), while 22% to 30% have secondary progressive MS (SPMS), all children at the Toronto clinic have RRMS. Primary progressive disease is relatively rare, and occurs in less than 5% of children diagnosed with MS. Because no centralized database exists and research on pediatric MS is scant, it is difficult to say whether incidence is rising, falling, or remaining stable, Ms. Boyd said.

Ongoing symptoms also are similar in the adult and pediatric populations. Besides the customary fatigue, these include cognitive deficits, heat intolerance, headache, tremors, seizures, and depression. Children with MS also appear to respond well to the same treatments, such as the disease-modifying therapies that are proving effective in adults.

For the most part, children tolerate the medications well, and in some cases seem to experience fewer side effects than do adults. For example, children who receive medication injections in the evening are more likely to “sleep through” certain side effects, Ms. Boyd noted, if only because children generally sleep more deeply than do adults. Even young MS patients can

learn to give themselves subcutaneous injections, which may promote a sense of independence and control. However, since none of the disease-modifying therapies has been studied systematically in children, she stressed the importance of closely monitoring liver functions, complete blood count, and any unusual symptoms during treatment.

Despite the lack of long-term studies on pediatric MS, there is some indication that the disease progresses less rapidly in children than in adults. Ms.

Boyd cited a recent Canadian study, based on the University of British Columbia's MS database, that gives reason for hope. The researchers found that 50% of MS patients with pediatric-onset disease switched from RRMS to SPMS after 23 years compared with 50% of patients with adult-onset disease, who switched after 10 years. Current and evolving therapies may offer reason for even more optimism, Ms. Boyd noted, because many of the patients in this longitudinal study may not have received the newer treatments now available.

Ms. Boyd concluded her presentation by stressing the need for greater awareness of pediatric MS among health care professionals so that diagnosis may be made earlier in the disease process and allow for better long-term outcomes. She also called for increased collaboration among pediatricians, pediatric neurologists, MS specialists, and other health care providers to better coordinate treatment for children with MS, especially with regard to pharmacologic and psychosocial issues.

MSX

—Bonnie Darves

Why Certify?

Acquiring the knowledge, skills, and experience that are required to practice as an MS nurse is no small challenge. Certification is a process that validates these competencies and gives MS nurses the formal recognition they deserve.

“The certified nurse brings a known expertise to patient care,” said Heidi Maloni, RN, MSCN, whose presentation at the IOMSN conference in Harrogate, United Kingdom focused on the importance of certification standards of professional nursing practice. “It

WHAT THE IOMSN EXAMINATION COVERS

- Basic concepts of MS (disease course classification, pathophysiology of MS, diagnostic process)
- Pharmacologic and nonpharmacologic treatment
- Symptom management
- Psychosocial intervention
- Research and education initiatives
- Patient advocacy

All candidates for certification must be registered nurses. It is recommended that they have at least two years experience with MS or neurologic nursing.

The next exam is scheduled for May 28, 2003 from 1 to 4 PM during the CMSC meeting in San Diego and also will be given nationally and internationally on May 31, 2003 at 8 AM. There is a \$250 examination fee. To obtain the handbook for candidates, which includes all application materials and a list of suggested readings and references, visit www.ptcny.com.

benefits the individual nurse to the full extent of professional expertise with impact on practice outcomes by establishing standards and recognizing nurses who meet those standards," she said.

The Multiple Sclerosis Nurses International Certification Board (MSNICB) was formed by the IOMSN to establish practice standards and domains of MS nursing practice that cross national borders and boundaries. During her talk, Ms. Maloni, who is Director of the MSNICB, discussed the four domains of MS nursing upon which certification focuses: clinical practice, advocacy, research, and education. She stressed the importance of certification as the MSNICB continues to institute stan-

dards in each of these domains, which are "considered the full range of MS nursing practices that may be called into use to serve the MS patient and his or her family."

It is important for MS nurses in all countries to become well-versed and remain up-to-date on such crucial issues as the disease's course and classification, pathophysiology, epidemiology, and distribution, Ms. Maloni noted. It also is important for MS specialists worldwide to share the growing body of knowledge and research about MS so that the most effective treatment plans may be developed and consequently standardized for optimal patient care.

The purpose of certification is to unite MS nurses from around the globe, to uphold standard practices based on common knowledge, skills, and tasks, to encourage best outcomes for the nurse-patient relationship, and to evaluate knowledge and practice through examination, noted Ms. Maloni. "Certification recognizes nurses who have met standards," she added. "By promoting the development of specialty nursing, certification encourages best practices."

MSX

CERTIFICATION BECOMES INCREASINGLY INTERNATIONAL

French-Canadian nurses Josee Poirier, BSN, and Jocelyn Frenette, RN, MSN, were the first to take and pass the IOMSN certification exam in a language other than English. By taking the test in French, they helped set the stage for future translations of the exam into other languages, which are to include Italian, Dutch, and Spanish.

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, or contact the organization at:

IOMSN

c/o Bernard W. Gimbel MS Comprehensive Care Center
718 Teaneck Rd, Teaneck, NJ 07666
(201) 837-0727