



IOMSN Update

Multiple Sclerosis Nursing in 2001: A Global Perspective

Reports From the IOMSN Annual Board Meeting February 2001

Educating the Newly Diagnosed

Florence, Italy—From the time of initial diagnosis of MS, nurses bear the major portion of responsibility for patient education. MS specialist nurses are the first health care professionals on the MS treatment team to encounter and assess the newly diagnosed. The relationships they develop with, and the trust they inspire in, the people with MS and their families may have significant impact on how well these individuals receive and respond to disease education.

“During the first months after diagnosis, people with MS are exposed to a great deal of information. It may be too much to assimilate, or they may be too frightened or confused to understand what they are being told,” said Barbara Johnson, RN, BSN, CRRN, Nursing Director at the Gimbel MS Comprehensive Care Center in Teaneck, NJ. “It may be necessary to titrate the information so the education process can proceed smoothly.”

The opportunity for education may arise when the MS treatment team and the person with MS are formulating a plan of care, which generally includes immunomodulating treatment. Because a newly diagnosed person is unfamiliar with im-

munomodulatory drugs, choosing among them will require assistance. This may be a suitable occasion to provide specific information, to write down instructions and demonstrate proper injection procedures, and possibly to acquaint individuals with educational materials available from the MS Society or on the Internet. The MS nurse will need to evaluate reactions and coping mechanisms carefully to determine both the individual’s and the family’s capacity to absorb the information being presented, keeping in mind that repetition may be necessary. As Ms. Johnson observed, “We have a wonderful opportunity to establish a strong therapeutic alliance with the newly diagnosed person and his or her family and friends.” She added that being realistic in early communications and treating members of the family unit sympathetically and with respect builds trust.

MS nurses fill roles that are essential in the education process of the newly diagnosed. These roles are represented in the mnemonic “FAC-CEM” (see sidebar, page 6), which is formed of six action words describing them: *facilitator*, *advocate*, *counselor*, *coach*, *educator*, and *manager*. “Educating people with MS about their disease makes them more likely to feel a sense of empowerment, acceptance, and well-being. We want them to learn as much as possible so

they will have the tools to care for themselves. We must help them and their families to establish reasonable expectations and realistic goals while offering encouragement and hope,” Ms. Johnson emphasized.

Reducing Anxiety in Persons With Relapsing MS

In relapsing forms of MS, some people recover fully between attacks or relapses, but others recover only partially, creating substantial anxiety for both the affected individuals and their health care providers. The fact that MS is unpredictable, with attacks appearing at random, also increases anxiety levels. According to Marie Namey, RN, MSN, Mellen Center for MS Treatment and Research, Cleveland Clinic, Ohio, “The questions most frequently asked by people with relapsing disease are: ‘What am I going to do now? Will I recover from this attack? How soon will I recover? What happens next?’”

Adding to the uncertainty is the worsening of disease with time. Most people who have MS are initially diagnosed with the relapsing-remitting form; however, after approximately 10 years, the majority find their disease course has become progressive, causing even more anxiety about the future. Now, they must deal with the advent of overt disability. Physical changes, altered self-image, and is-

"FACCEM" DEFINES THE KEY ROLES OF MS NURSES

Facilitator: connecting the person with MS and his or her family with members of the MS treatment team. For example, arranging appointments with a rehabilitation therapist for a patient who needs physical therapy or counseling sessions with a social worker—or enabling their access to information—for a family disrupted by fear and anxiety.

Advocate: supporting or pleading the cause of a person with MS to the health care system. This may mean making telephone calls or writing letters to help obtain services, medications, or equipment not covered by health insurance or—for those who do not have insurance—organizing pro bono care.

Counselor: providing anticipatory guidance; foreseeing and forestalling problems. This may entail finding a support group for the patient, the family, or both. In the absence of social workers, the nurse must provide emotional support and help patients and their families to cope with the changes affecting significant areas of their lives.

Coach: guiding, educating, listening, and encouraging those with MS. For example, helping them to organize a plan of care or showing them how to obtain and use immunomodulating drugs.

Educator: providing factual and comprehensive information about MS symptoms, immunomodulatory drugs, medications and therapies for treating symptoms, safety issues, available services, and assistive devices. This requires MS nurses to possess a thorough understanding of the disease process and the impact of MS on quality of life, which may involve physical, emotional, and cognitive issues.

Manager: advising adherence to a prescribed drug regimen, monitoring medication side effects, managing the course of disease, and informing the patient about what's happening as symptoms appear and disease progresses. MS nurses also provide encouragement and emotional support as part of their management strategy.

sues of autonomy versus dependence appear, along with worries about recognizing and living with cognitive impairment. "Employment is a major concern for people with progressing MS. They don't know how long they will be able to function at work, or even if their condition will permit them to continue to drive. They worry that they will lose their jobs, spouses, and families," Ms. Namey explained.

"Psychological distress is not limited to the person who has the disease," she added. "Many times, it is family members who are affected by the worsening health status of their loved one or by the changing social roles being forced upon them." Other fears are common to persons with MS and families: They have seen other people with MS while sitting in clinic waiting rooms and know that some form of disability—possibly severe—is likely. These fears may or may not be verbalized.

"It is part of our duty as MS nurses to bring these fears into the

open and to assist with the challenges of coping," Ms. Namey advised. She underscored education as the means to dispel fears and anxiety and to provide reassurance and guidance. While patients and their families have the experience of only one, MS nurses have garnered knowledge and experience from the significant number of people they have treated; sharing that experience may help to allay psychological distress. "Our nursing response to anxious patients and families should be to provide educational information, rephrasing and repeating it to reinforce what they have already heard. It's also helpful to furnish written information and instructions for later reading, because anxiety, sadness, or fear may be so strong that verbal education is not well received," she said.

What Are the Information Needs of MS Nurses?

Chronic illnesses like MS have been characterized by a disease course that may change over time but that can be

shaped and managed, even if the eventual outcome cannot be altered. What skills and knowledge must MS nurses possess to meet the standards of "best practices" in a model of nursing care that will help to shape the disease course?

"First, MS nurses must have extensive knowledge about the disease and its symptoms, the diagnostic process, and the classification of MS stages and related levels of disability," said Kathleen Costello, RN, MS, CRNP, Maryland Center for MS, University of Maryland, Baltimore. She noted that information sharing is a crucial element in developing relationships between the person with MS and the MS nurse, the person and the physician, the physician and the MS nurse, and the MS nurse and the family. "To establish trust in our nursing abilities and to empower people with MS, we must be able to answer the questions that will arise from the onset of MS, through progression, and into the advanced stages. We need to understand the ways in

which this disease impacts the person with MS and his or her family members and/or care partners.”

MS nurses must be thoroughly educated in the pharmaceutical interventions for MS—both immunomodulatory and symptomatic—and be able to provide practical information about indications for their use, their effectiveness, and any associated side effects. These health care professionals should also be familiar with nonpharmacologic strategies of rehabilitation, such as physical and occupational therapy, speech therapy, and the fitting and use of assistive devices. They must be well apprised about the availability of community resources and services that help make such rehabilitation strategies accessible to people with MS.

“It’s important to stay current with the results of recent research in MS and the immune system and with experimental studies involving new drugs and the recombination of older drugs,” Ms. Costello stressed. She emphasized that MS nurses must consider the principles and ethics of patient care: to do no harm and to respect the individuality of each person with MS, to be honest and fair, and to maintain confidentiality.

“So how do we get the information we need?” she asked. “Certainly, from forums just like this: from formal conferences and informal discussion groups involving our peers.” Additionally, Ms. Costello recommends listening to people with MS to learn how the disease affects their lives, networking with other MS nurses, and surfing the Internet for relevant MS and neurology sites. “There are also many MS journals and publications we can read in our

copious spare time,” she said facetiously. “Above all,” she concluded, we must stay involved—with patients, peers, and our profession.”

Developing a Global MS-Nursing Network

The development of a workable, worldwide MS nursing network is being fueled by an increasingly global approach to MS care and MS nursing practices and standards. In the opinion of Kaye Hooper, RN, RM, MPH, of the MS Clinic, Royal Brisbane Hospital, Queensland, Australia, “The primary aim of a global [MS nursing] network must be to benefit our patients, to equip and support nurses, and to provide quality care for people with MS.” Other aims are to provide peer support and mentoring and to permit personal and professional interaction among MS nurses from various countries—enabling them to exchange information and encourage each other.

Information exchange is key. With it, “we can enhance our base practices, augment our research, and nurture our professional growth,” Ms. Hooper stated. For example, she explained, it was enlightening to hear during a conference workshop about ways in which European colleagues cared for people with severe disability owing to MS; it underscored the fact that cultural distinctions must be considered and handled sensitively.

Ms. Hooper’s overview of a productive global network included several principles. First, it must be accessible and affordable so nurses in remote areas having few resources may participate as well as do nurses in technology-oriented countries. “If

an extremely expensive piece of computer equipment is required, some nurses would be excluded by default,” she noted. Second, the information available on the network must be appropriate to the country or region in which it is being accessed. Health-insurance issues are not a major concern for nurses in Australia, Canada, and the United Kingdom, where government subsidizes national health care (in contrast to the United States). Finally, the network must be equitable, with sufficient international representation. “We need to consider the whole of our group membership in order for nurses from around the world to identify with it,” Ms. Hooper emphasized.

“A global network needs to be established from the bottom up,” she related. It must start in regional groups, with diverse regional representatives, and expand to include all the regions in a country. Networking must be country-specific, because the role of nurses in Australia differs from that of nurses in the United States, or in Italy. Only then can an international advisory council be truly representative of international MS nursing. Health care systems differ by country, too, and may dictate what nurses can and cannot do in their clinical practices.”

These are some of the challenges that must be faced, Ms. Hooper believes. However, the benefits of collaboration, such as sharing in research projects and research funding when some countries are resource rich and other are resource poor, are wonderful motivators. In closing, she pointed out that, “A global network can play a role in improving the quality of care for people with MS.”

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Advanced MS Causes Nurses to Redefine Their Therapeutic Partnerships

By the time the advanced stage of multiple sclerosis (MS) presents, patients are severely disabled, and care changes from treatment in an MS center or outpatient clinic to palliative care in a hospital or long-term-care facility. Advanced disease requires MS nurses and caregivers to modify the treatment strategy.

"In advanced MS, the ongoing care needs to shift to providing comfort, ensuring safety, and preventing complications," according to Colleen Harris, who is Nurse Coordinator at the University of Calgary MS Clinic in Alberta. "Loss of control makes it imperative that care be planned and implemented with consideration of individual choice, cultural preferences, and previous lifestyle."

The main role of an MS nurse becomes provision of sustaining care and maintenance of a positive sense of well-being in persons with advanced MS, since these individuals are very vulnerable to secondary illnesses. Respiratory complications usually arise from chest-wall weakness and can turn a simple cold or flu into a serious case of pneumonia, which is one of the leading causes of death among persons with advanced MS. The MS nurse or physiotherapist should make sure that both the person with MS and his or her caregiver are familiar with deep breathing and chest physiotherapy techniques. Pneumonia vaccine use among this population is controversial, but "it may make the difference between life and death," added Ms. Harris. (The controversy arises because of concern that vaccinations may cause or trigger attacks of MS, but two separate reports in the February 2001 issue of *The New England Journal of Medicine* indicate no association.)

Persons with advanced MS also have difficulty swallowing. Many of these individuals are "silent aspirators." (They unknowingly draw food into their lungs.) If there is a speech problem, or if the caregiver or individual with advanced MS suspects there are swallowing difficulties, Ms. Harris recommended speech and swallowing assessments. Dieticians and speech therapists can create diet programs that will help alleviate most of these problems.

Urinary tract infections are common throughout the course of MS but can become deadly during the advanced stage of MS. MS nurses must educate caregivers to look for any signs of infection, such as the urine ap-

pearing cloudy, an indication of the presence of pus in the urine.

In advanced MS, spasticity may lead to skin breakdown. Also, decubitus ulcers (bedsores) may develop because the person is often nonambulatory during this stage of MS. Reclining wheelchairs—while expensive—have the ability to tilt back, which can help to prevent circulatory problems resulting from venous pooling and edema in the extremities. Range-of-motion exercises can also prevent contractures.

Persons with advanced MS and their families are often forced to deal with many end-of-life issues. Spirituality, hope, and humor all become extremely important when MS progresses to this stage. According to Ms. Harris, "It's more than just their religious preferences—it is recognizing that perhaps life is going to be over in a few years—and making decisions and coming to terms with this realization." Because cognitive decline can occur during this stage, people with MS should consider signing advance directives and organizing financial matters before cognitive ability deteriorates.

Perhaps most important, according to Ms. Harris, "There has to be a concern for dignity. Persons with advanced MS have lost their control. They have to try to maintain their dignity and privacy as much as possible." Ms. Harris concluded, "The model of palliative care, which is a very supportive model, works well and provides a philosophy that nurses should follow in advanced MS." MSX

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