



Multiple Sclerosis Nursing in 2005: A Global Perspective

Energy Conservation Techniques in MS

According to the National Multiple Sclerosis Society, up to 80% of people with MS experience fatigue. Distinct from run-of-the-mill "tiredness," MS-related fatigue tends to occur more suddenly than normal fatigue, tends to worsen as the day progresses, and is often aggravated by heat and humidity. Although clinicians often employ pharmacologic methods to combat fatigue, nonpharmacologic techniques such as energy conservation may be effective.

"An occupational therapist (OT) can provide a thorough assessment and help MS patients to develop techniques to conserve their valuable energy," explained Jutta Hinrichs, BScOT, of the Foothills Medical Centre in Calgary, Alberta. "We usually start by asking patients to prioritize their activities," Ms. Hinrichs said in an interview with *MS Exchange*. "We advise them to pace themselves throughout the day and to perform most of the heavy or complex work in the mornings, when they are likely to have more energy."

Ms. Hinrichs also advised that patients alternate activities with short breaks, such as performing an activity for 45 minutes and then taking a 15 minute rest break. Patients with MS-

related fatigue tend to "hit the wall" mentally. "How they handle the emotions that accompany this is key," she said. "If people are not able to physically finish a chore, it's important that they mentally let it go. Sitting and stressing about what remains to be done just uses up more energy." Patients also need to learn their tolerance levels and heed the warning signs if they start to exceed them.

"A lot of fatigue management comes down to making choices," Ms. Hinrichs said. "For example, work is so important to some people that they will push themselves at their job all day, and then come home and crash." She noted that whether or not this would work for someone would depend on what activities that person had to do when arriving at home, such as preparing dinner or taking care of children, and whether the people he/she lives with are willing to pick up any slack. "It's very important for individuals with MS who are experiencing fatigue to communicate their needs to those around them and to be cognizant of the choices that they're making."

Energy Conservation Trial

Much of Ms. Hinrichs' advice has been borne out in recent studies of energy conservation programs for people with MS. Virgil Mathiowetz, PhD and colleagues performed a randomized controlled trial to test an energy

conservation course developed in 1995 by Packer et al. The course was an experimental intervention designed for persons with chronic fatigue secondary to a chronic illness. Six weekly two-hour group sessions were led by OTs and included seven to 10 participants. "Some topics covered in the course included the importance of resting throughout the day, proper body mechanics, modification of the environment, and use of energy-saving devices," said Dr. Mathiowetz.

One hundred sixty-nine MS patients were randomly assigned to one of two groups. Group A received the educational intervention immediately, while Group B received the intervention seven weeks later. Study participants were assessed using the Fatigue Impact Scale, the Short Form-36 Quality of Life measure, and the Self-Efficacy for Performing Energy Conservation Strategies Assessment. Dr. Mathiowetz and colleagues concluded that the course helped decrease fatigue impact and increased some aspects of quality of life and self-efficacy. The researchers will present one-year follow-up data at the upcoming CMSC conference in Orlando.

Dr. Mathiowetz hopes to investigate the energy conservation course with other populations, including patients with cancer or HIV/AIDS and elderly patients. "We're also looking into developing different

formats of the course, such as a teleconference session," he said.

"One possible reason for the success of the course is the group format; it decreases participants' sense of isolation," Dr. Mathiowetz explained. "The individuals were supported by their peers in their efforts to change their behaviors and manage their fatigue." Most importantly, he stressed, this trial supports the idea that energy conservation techniques taught by OTs are a legitimate, non-pharmacologic way for patients with MS to manage their fatigue.

"When working with patients who have MS-related fatigue, we often use a banking analogy," explained Dr. Mathiowetz. "People with MS have a limited amount of energy, just as a bank account has a certain amount of money to work with. The key is for individuals to save energy when they can and to budget energy for the activities that are most important to them."

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Caring for People With Advanced MS

People with primary progressive or secondary progressive MS will most likely, at some point in their disease progression, develop symptoms that require specialized care and medical equipment. Helping to manage such complications can be a challenge for clinicians involved in the care of these patients.

To compound this problem, relatively little research has been devoted to issues faced by those in the later stages of the disease, according to Jodie Haselkorn, MD, MPH, Associate Professor of Rehabilitation Medicine at the University of Washington in Seattle. Dr. Haselkorn and colleagues will present "Caring for People With Advanced MS" at the upcoming CMSC meeting in Orlando. This workshop will focus on the issues faced by those with advanced MS, their caregivers, and the clinicians who treat them.

"Patients in the advanced stages of MS may have serious impairments and disabilities," said Dr. Haselkorn, who is also Director of the Veterans Health Administration

MS Centers of Excellence West, located in Seattle and Portland. "These may include severe fatigue, cognitive dysfunction, visual difficulties, swallowing difficulties, speech and communication problems, pulmonary limitations, bladder and bowel impairments, sexual dysfunction, spasticity, loss of mobility, and the inability to be independent in self-care." Dr. Haselkorn and her colleagues reviewed the available literature in an effort to determine what is-

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sues people with advanced disease consider most important. Not surprisingly, these patients have emotional as well as physical problems.

"Some of the emotional concerns encountered by people with advanced MS include depression and perceived loss of dignity due to increased dependence on others," added David Gruenewald, MD, an Associate Professor in the Division of Gerontology and Geriatric Medicine at the University of Washington School of Medicine. "These individuals also may have difficulty in accepting losses and experience a sense of lack of control in the face of this progressive and often unpredictable disease."

James Bowen, MD, Co-Associate Director of Clinical Care for the VA MS Center of Excellence West and colleagues conducted a survey of MS patients regarding end-of-life issues. According to the survey, those with advanced MS seem to hold a more negative view of adult care facilities than do other groups, such as the elderly. "People with MS seem to view the care provided in long-term care facilities as suboptimal," he said. "However, most respondents reported that they would be more willing to attend such a facility if it specialized in MS care."

The researchers also looked at attitudes regarding cardiopulmonary resuscitation and other end-of-life issues, which have figured prominently in the public mind lately due to high-profile cases in the news. "The majority of patients surveyed support physician-assisted euthanasia, although very few said they would seek this service for themselves, no matter what their medical condition,"

Dr. Bowen reported. He added that this might simply reflect patients' desire for control, rather than fear of pain. "Patients probably just like knowing that the option is available, even if they would never actually use it." The presence of depression did not seem to influence respondents' opinions on this matter. Surprisingly, those with greater disability were less likely to endorse euthanasia.

As Dr. Gruenewald noted, patients in the advanced stages of MS express a wide variety of unmet needs for medical and community services. "In contrast to studies of people with more life-threatening conditions, such as cancer, end-of-life care issue did not emerge as very significant," he said. Respondents did not deem issues such as advanced care planning and fear of dying to be very important, though some did mention the role of religion and/or spirituality. "To our knowledge, no work has yet been published regarding the quality of dying in people with MS," Dr. Gruenewald added.

"Although we received a good deal of information from the survey, more research needs to be done in this area, so that better clinical management strategies can be developed," said Dr. Bowen. "By studying the factors deemed important by patients with MS in advanced stages of the disease, we hope to improve their quality of life."

The workshop was organized by the VA MS Centers of Excellence and will take place on Friday, June 3. **MSX**

Mobility Aids and Assistive Technology for MS Patients

Many MS patients develop a level of disability that interferes with activities of daily living. While they may benefit from the use of assistive technology (AT) and/or mobility aids, a great number are not using this equipment. This may be because they are embarrassed to be seen using the devices, cannot afford them, or simply do not know that such aids exist. To help with the latter problem, Carrie Bruce, MA, CCC-SLP, ATP and Pat Provance, PT will explore the latest options in their presentation, "Mobility Aids and Assistive Devices," at the upcoming CMSC conference in June.

Tools to Make Life With MS Easier

The Technology Related Assistance for Individuals With Disabilities Act of 1988 defines AT as "any item, piece of equipment, or product system . . . used to increase, maintain, or improve functional capabilities of individuals with disabilities." According to Ms. Bruce, Research Scientist at the Georgia Institute of Technology in Atlanta, this act was established to provide each state funding for services provided to individuals in need of AT. "Many assistive items can be bought at a local store; AT consists of both high-tech and low-tech items," explained Ms. Bruce, in an interview with *MS Exchange*. "It can be something as simple as a jar opener, or something as advanced as a computer program that allows the cursor to follow the movements of the user's eye."

"These days, most requests for assistive technology seem to involve ways to help access the computer or telephone," she said. For individuals with MS, being able to use phones and especially computers is vital. The Internet provides MS patients with the ability to socialize, connect with peers who can provide support, and learn more about the disease.

AT may also foster greater independence for those with the disease. For example, certain devices allow patients to have greater control over their environment. "As long as a person has a consistent, controlled, movement that he or she can independently produce, be it a breath or an eye movement, the person can gain access to a computer or other environmental control device," noted Ms. Bruce. Everyday tasks, such as opening blinds or making coffee, can then be programmed to run via the user's computer.

Unfortunately, Ms. Bruce explained, many MS patients simply may not know where to find financial assistance if necessary. Some states and organizations provide

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funding or alternative financing plans; the person is sometimes able to receive a loan to help pay for the equipment. There may be a waiting period to determine eligibility with some programs. In addition, it may be difficult to get third party payers to provide for assistive devices. "However, if a device is determined medically necessary, such as using a telephone or computer to communicate health care needs, a provider may cover some of the cost of the item," Ms. Bruce explained.

Medical necessity must be determined by a clinician. To meet this criteria, a device must be used to restore or approximate normal function of a missing, malformed, or malfunctioning body part and be directly related to a diagnosed medical condition and expected to improve the user's ability to function. The device must be able to withstand repeated use, be primarily used for a medical purpose, and be appropriate for use in the home, she added.

Keeping People Mobile

"Although many people with MS feel a wheelchair is a sign of defeat, mobility devices actually help people to keep their independence," said David Marriott, MS, PT, ATP, in an interview with *MS Exchange*. Selection of the right mobility aid for a person with MS may involve meetings among occupational therapists, physical therapists, speech/language therapists, and equipment dealers. "It's difficult at times to coordinate so many people," Mr. Marriott said, "but doing so will provide a better chance that the person will receive a device that comes equipped with adaptations that may be needed in the future."

Many people with MS initially request a scooter in an attempt to avoid any perceived stigma that may surround using a wheelchair, explained Mr. Marriott, who is an equipment dealer at Chesapeake Rehab Equipment in Baltimore. "This is often a mistake, as some insurance companies may require a person to own a mobility aid for up to five years before they will fund another one," he stated. If that person progresses quickly, he or she may soon find the scooter, which requires more upper body function and trunk control, to be virtually useless.

"Many health care providers are unfamiliar with such equipment and are unaware of the options available for people with MS," Mr. Marriott said. "For example, power wheelchairs may be outfitted with alternative controls that are worked by a person's head or fingers, if there is good control in these areas."

Mr. Marriott also stressed the importance of referring patients to a qualified equipment dealer. "Clinicians should work only with dealers who have a good reputation and have gotten positive results for other customers," he said. He advised that it might be worthwhile for clinicians to check with local rehab hospitals, as they will be more likely to know who the good dealers are. "There are also organizations that provide certification for a minimal level of training and competency," he explained.

"MS patients should be aware that today's mobility aids are more versatile and come with more features than ever before," he concluded. "The technology behind these devices is often amazing."

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—Krista Binetti

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