Once largely ignored, if not outright dismissed by most health care providers, complementary and alternative medicine (CAM) has become more popular now than ever. Patient use of herbal and other CAM remedies has risen significantly in recent years and those with multiple sclerosis (MS) are no exception.

**Popular Among MS Patients**

“Studies have routinely found that the majority of people with MS have tried some form of alternative therapy,” noted Allen Bowling, MD, PhD, Medical Director of the Rocky Mountain Multiple Sclerosis Center in Englewood, Colorado and Clinical Associate Professor of Neurology at the University of Colorado Health Sciences Center. Of the 3,140 respondents to a 2003 survey of MS patients, 57% reported using one or more CAM therapies.

CAM use by MS patients was quite common during the 1970s, because clinicians had little to offer these individuals other than symptomatic management, noted June Halper, MS, CN, ANP, FAAN, Executive Director of the Bernard W. Gimbel MS Comprehensive Care Center in Teaneck, NJ. “Some of our patients would spend fortunes on totally unproven therapies such as cobra venom or elemental calcium,” she recalled. Today, the limitations of certain disease-modifying therapies—and the increased acceptance of CAM by health care professionals—have ensured that alternative therapies remain on the radar screen for most patients.

**Helping Patients Make Informed Decisions**

“There are very few alternative therapies for which definitive evidence of efficacy exists,” Dr. Bowling admitted. Therefore, health care providers may feel that discussing alternative medicine is a waste of the patient’s time. However, even MS clinicians who are skeptical about the efficacy of CAM may find a working knowledge of alternative therapies valuable. “We do know about many alternative therapies that could possibly be helpful—or harmful—and we can improve quality of care by sharing this information with our patients,” said Dr. Bowling.
For example, some CAM therapies have immune-stimulating properties that could, in theory, provoke or worsen the symptoms of autoimmune diseases such as MS, added Dr. Bowling (Table).3

Other alternative therapies can have adverse effects not unlike those of conventional medications. For instance, gingko can increase the risk of bleeding and thus should be avoided by people who are using anticoagulants or have bleeding disorders. To cite a more extreme example, kava kava, used to treat mild anxiety, has been linked to fatal liver toxicity and has been banned in Canada and some European countries.

“Thus, it is important that clinicians educate their patients on any side effects or interactions that may occur,” stressed Dr. Newland.

**CAM AND THE MS TREATMENT PLAN**

In formulating a treatment plan, Dr. Bowling advised focusing first on conventional pharmacologic therapies as well as accepted adjunctive approaches, such as physical therapy. “However, if patients ask whether there is anything else they can do, information about various interventions can be provided.” Clinicians should be sure to stress that evidence-based data on CAM therapies are often limited, Dr. Bowling said.

While Dr. Bowling’s center provides printed material and references for patients interested in a particular CAM modality, personal discussions with patients are invaluable. “If we’re able to talk with patients about alternative therapies and make them aware of what might be helpful and what might be harmful, we can improve the quality of care that we provide,” he said.

**CAM Therapies of Note for the MS Practitioner**

Following are some biologic and other CAM therapies that—because of their effectiveness, potential for adverse effects, or popularity—may be of interest to clinicians who treat MS patients. For more information about these and other CAM therapies, see the resource listing on page 3.

**Acupuncture**

One large study of acupuncture in MS patients showed improvements...
in symptoms such as pain, fatigue, spasticity, and bowel problems; however, the study did not include a control group. More rigorous trials are under way.4

Acupuncture is usually well tolerated. When performed by a trained practitioner, serious side effects are rare.5

Cold Remedies
It has been suggested that influenza and the common cold might worsen MS symptoms or trigger attacks. However, some CAM therapies for treating or preventing respiratory infections, such as echinacea, may pose similar risks because of their immunostimulatory effects (Table).

Vitamins/Calcium
In addition to helping maintain bone density, vitamin D may have mild immunosuppressive effects, which could be beneficial in MS (though no studies have confirmed such benefits).

Because research suggests that oxidative stress may play an important role in the etiology of MS,6 it has been suggested that supplements containing antioxidants (such as vitamins A, C, and E) may also be beneficial to persons with MS. However, there is no evidence to support this theory. “Moreover, antioxidants increase the production and activity of immune cells and thus pose a theoretical risk to MS patients,” said Dr. Bowling. “In addition, high intake of vitamins A (> 10,000 IU/d) can be toxic and doses of vitamin C above 1,000 mg per day can cause nausea and diarrhea.”

Psyllium
Because many patients with MS experience constipation, psyllium (a form of dietary fiber) may be a useful symptomatic therapy.

St. John’s Wort
Often used for mild depression, this herb should be taken under the guidance of a clinician because it is a cytochrome P450 inducer that alters the metabolism of many drugs. It may also be sedating.

Dietary Fats
The omega-3 and omega-6 polyunsaturated fatty acids (PUFAs) are the best-studied nonpharmacologic therapy for MS. One randomized trial involving 312 patients found a statistical trend (P = .07) for a lower progression rate in persons with MS treated with a combination of eicosapentaenoic acid and docosahexaenoic acid.7 Epidemiologic evidence is consistent with these findings: countries with a high intake of polyunsaturated fatty acids have relatively low rates of MS.8

The best dietary source of omega-3 PUFAs is fatty fish, said Dr. Bowling, though supplementation with fish oil is necessary to attain the intake levels used in most studies. Most Americans receive an adequate supply of omega-6 PUFAs from dietary sources. “As regular use of PUFA supplements may cause deficiency in Vitamin E, modest supplementation (100 IU/d) is desirable,” he added.

Note: Dr. Bowling will chair a symposium on CAM at the 2006 Annual Meeting of the CMSC.

REFERENCES

For more information

Cerebellar ataxia (CA) affects many individuals with multiple sclerosis (MS). However, relatively few studies of pharmacologic and surgical therapies in the treatment of this disorder have been conducted, reported Jon Marsden, PhD, at the Ninth Annual Conference of the MS Trust in Blackpool, United Kingdom. Moreover, most forms of physiotherapy and occupational therapy for CA have never been formally tested in persons with MS. As a result, little is known about the optimal treatment of this condition.

The symptoms of CA include tremor, dysmetria (inability to estimate the size of a movement, often leading to overshooting a target), and dysynergia (inability to coordinate voluntary muscle movements, resulting in unsteady motions and staggering gait). However, “not all that wobbles is cerebellar ataxia,” emphasized Dr. Marsden, who is a Medical Research Council Clinician Scientist Fellow in the Department for Motor Neuroscience and Movement Disorders at the Institute of Neurology in London. For example, ataxia can also result from vestibular dysfunction or sensory loss. Determining the cause of ataxia is very important, however, because treatment differs according to etiology.

IDENTIFYING CEREBELLAR ATAXIA
The underlying cause of CA is damage to the cerebellum or its associated pathways, such as the neurologic damage caused by MS, explained Dr. Marsden. The cerebellum may be involved in controlling coordination, timing, and motor learning. As such, CA can impair a variety of functions beyond mobility, including communication, feeding, and other activities of daily living. MS patients with CA tend to have poorer functional recoveries from exacerbations than do patients without CA.

MAKING A DIAGNOSIS
Techniques for assessing CA include the International Cooperative Ataxia Rating Scale (ICARS), which features subscales for postural disturbance, limb movement, oculomotor disorders, and speech disorders. This test is reliable and is sensitive enough to be able to tell the difference between cerebellar disease and conditions that may mimic it,” Dr. Marsden noted. Nonetheless, the ICARS has been used primarily in research rather than as a clinical tool.

Timed tests (eg, walking) and performance measures (eg, target pointing tests) may also be useful in a clinical setting but are nonspecific. For example, they don’t differentiate between slow walking caused by CA and that due to sensory loss resulting from MS.

PHARMACOTHERAPY AND SURGICAL INTERVENTIONS
Because cerebellar function depends on a variety of neurotransmitters (eg, glutamate, noradrenaline, serotonin), there are, in theory, several targets for pharmacologic therapy. In practice, however, the drugs that have been used to treat CA in MS may work in certain cases but are not very effective as a whole. “The most-studied agent has been isoniazid; however, all studies of the drug have been small and have yielded conflicting results,” noted Dr. Marsden.

Surgical procedures used to treat CA include thalamotomy (surgical ablation of a portion of the thalamus) and thalamic stimulation, in which an electrode implanted in the thalamus is connected to a power supply (usually placed in the chest) that can be activated as desired. Although these procedures can be successful in improving tremor, the improvement is often short-term. Moreover, even if the tremor improves, the gain in motor function may be minimal, particularly if the patient also has dysmetria and dysynergia. Morbidity from the procedure, continued on page 9
IOMSN Launches Advanced Practice Nursing Program

A new comprehensive educational program in MS Advanced Practice Nursing was formally launched in December. This initiative is designed to provide advanced practiced nurses (APNs) the opportunity to develop the skills and knowledge necessary to provide the highest quality of specialized MS nursing care, according to Colleen Harris, RN, MN, MSCN, Chair of the program’s application committee.

Jointly sponsored by the International Organization of MS Nurses (IOMSN) and Holy Name Hospital in Teaneck, NJ, and supported by an educational grant from Teva Neuroscience, the APN educational program will follow the model used for the IOMSN’s very successful nurse mentorship program, Ms. Harris said.

Tailored to Nurses’ Needs

Upon applying to the program, candidates will complete a questionnaire designed to indicate whether their needs will be best met in a research or a clinical track. “In the research track, learners will work at an academic center with an APN who is experienced in conducting nursing research,” explained Ms. Harris. “In the clinical track, learners will ‘shadow’ an experienced APN in his or her clinical practice. The goal is to enhance the learners’ skills in diagnosing MS, managing patients’ symptoms, and treating patients who receive disease-modifying therapy.”

The first part of the three-phase program will consist of a three-day session at an assigned MS center or research facility, depending on which track the learner chooses. Phase II will consist of follow-up sessions between the learner and his or her advisor. “These meetings will be customized to the needs of each pair and may take place in person, or via the telephone or e-mail,” said Ms. Harris. During phase III, expected to take place 12 to 18 months after the program’s start, learners will meet as a group in a central location to share their accomplishments, evaluate the program, and receive presentation and leadership skills training.

Through this initiative, learners will be provided the chance to begin networking within the APN community.

At the end of the program, each learner will be awarded a certificate. He or she may also be eligible to sit for the MS Certified Nurse (MSCN) exam and to receive funding to cover the exam’s registration fee.

Qualifications for Participants

The IOMSN is currently seeking MS nurses who want to work with a more experienced APN as part of this program, as well as APNs to serve as advisors.

Learners must hold an RN or approved equivalent; have at least two years of nursing experience; have a Master’s Degree in Nursing or Certification in Advanced Practice Nursing; actively work with MS patients; possess credentials as required by each state; and be an IOMSN member in good standing.

To qualify as an advisor, each applicant must hold a Master’s Degree or its equivalent; possess appropriate credentials as determined by each state; be a member of the IOMSN in good standing; actively work with MS patients in clinical practice or in a research setting; and have a minimum of five years of experience in MS research or patient care. Having an MSCN certification is preferred.

Application forms may be downloaded from the IOMSN’s Web site at www.iomsn.com.

—Krista Binetti
Visual Dysfunction in MS

Disturbance of vision is one of the most common manifestations of multiple sclerosis (MS) and is experienced by up to 80% of patients during the course of their disease. For many, it is the initial clinical symptom. "MS can affect any portion of the visual sensory system in ways that can result in significant disability, greatly compromising a patient’s ability to work and to engage in activities of daily living,” said Elliot Frohman, MD, PhD. “Although many of these conditions are self-limiting, certain aspects of vision may never return to previous levels.”

Types of Visual Dysfunction

Optic Neuritis

Optic neuritis—or inflammation of the optic nerve—affects up to 55% of those with MS at least once during the course of their disease, according to Robert Shin, MD, Assistant Professor of Neurology and Ophthalmology at the University of Maryland School of Medicine in Baltimore. It is also the first symptom of MS in many cases. According to the Optic Neuritis Treatment Trial, 56% of patients with acute optic neuritis who also had one or more white-matter lesions on their baseline brain MRI scan developed MS within 10 years, in contrast to 22% of optic neuritis patients who had a normal baseline scan.

Typically, optic neuritis manifests as an acute blurring, graying, or loss of vision in one eye; both eyes are rarely affected. “The condition usually resolves by itself within four to 12 weeks,” said Dr. Frohman, who is Professor of Neurology and Ophthalmology and Director of the MS Program & MS Clinical Center at the University of Texas Southwestern Medical Center, Dallas. However, the quality of a patient’s vision—including color perception, depth perception, and contrast sensitivity—may be reduced indefinitely.

Interestingly, it is possible for a patient to experience inflammation and/or demyelination of the optic nerve without experiencing any appreciable visual dysfunction. “In such cases, visual evoked potential (VEP) testing demonstrates lesions on the optic pathways, despite a patient’s reported lack of symptoms,” Dr. Frohman said. A positive VEP may be useful in the diagnosis of MS, as it can provide evidence of a second demyelinating event, even if the patient is not experiencing symptoms.

"Some studies suggest that MS patients who experience optic neuritis as an initial clinical event have a more favorable prognosis than those who present with visual problems likely to result from brainstem dysfunction, such as diplopia or nystagmus, early in the disease. However, this has not been definitely proven,” added Dr. Shin.

Eye Movement Abnormalities

“Approximately 75% of MS patients demonstrate some type of eye movement abnormality,” said Dr. Frohman. Such ocular dysfunction may correlate with poor disease prognosis: In one study of 50 MS patients, those with abnormal eye movements were significantly more disabled than those with normal eye function.

One common type of eye movement abnormality is nystagmus, a repetitive, back-and-forth movement of the eye(s). “This can reflect abnormalities in the mechanisms that hold images on the retina,” Dr. Frohman explained.

“Nystagmus may result from an MS attack in the vestibular part of the brainstem or the cerebellum or may occur in the setting of internuclear ophthalmoplegia (INO),” added Dr. Shin.

Manifesting as a weakness or paralysis of eye movements and occurring in approximately one third of MS patients, INO is also a common cause of diplopia, or double vision, which occurs when the eyes are not moving in tandem.

Other symptoms of INO include blurred vision and oscillopsia (rotating, circular eye movement). When both eyes are affected, some degree of demyelination is indicated. “However, many patients with INO may present without symptoms, or with a ‘blur’ instead of true double vision,” said Dr. Shin.

Diagnosing Visual Dysfunction in the MS Patient

A definitive diagnosis of visual dysfunction can often be made through a clinical examination that includes a thorough history, explained Dr. Frohman (Table).
For example, most patients with optic neuritis will present with a reduction of central acuity. “Patients may complain of difficulty in seeing other people’s faces, or report that there is a ‘line’ in their center of vision,” noted Dr. Shin.

On examination, a patient with optic neuritis may have an afferent pupillary defect, or asymmetry in the pupils’ reaction to light, Dr. Shin explained. Diagnosis of the condition can be confirmed with VEP, or T1-weighted MRI with gadolinium infusion, Dr. Frohman added.

During a clinical visit, a patient may demonstrate an obvious dysfunction in eye movement. “However, a misalignment may be difficult to detect without the use of ophthalmologic tools,” admitted Dr. Shin.

Double vision, usually identified by the patient, may be easily confirmed by the clinician. “An important question to ask patients who complain of double vision is whether the problem disappears if either eye is closed,” said Dr. Shin. If so, diplopia is confirmed.

**Treatment**

“For optic neuritis, corticosteroids are the cornerstone of therapy,” stated Dr. Shin. “Although they don’t appear to improve visual outcome in the long run, they do seem to speed visual recovery.”

Diplopia often resolves on its own, though corticosteroids are often prescribed in an attempt to hasten restoration of normal vision. “Use of an eye patch is guaranteed to temporarily ‘cure’ diplopia, but some patients may feel self-conscious while wearing it,” said Dr. Shin. Prisms can also be added to an existing eyeglass prescription to alleviate double vision. In rare cases, strabismus surgery may be attempted to realign the eyes.

Treatment of nystagmus is challenging, as most pharmacologic agents are only moderately effective, said Dr. Frohman. Baclofen, clonazepam, gabapentin, and scopolamine provide some benefit in selected patients. In rare cases, surgery may help.

While visual symptoms are very common in the MS population, most dysfunction is self-limiting and rarely results in total blindness, stressed Dr. Shin. “By inquiring about visual disturbances and referring patients to a neuro-ophthalmologist when problems are suspected, MS nurses can help patients have the best possible prognosis.”

**References**


**Suggested Reading**


**Table IDENTIFYING VISUAL DYSFUNCTION IN THE MS PATIENT**

According to Dr. Shin, there are several ways an MS nurse can identify possible visual dysfunction during an office visit. Some of his recommendations:

- Take a careful history. Ask the patient to describe any visual problems he or she is having.
- Determine whether the visual problem is present in only one eye, both eyes individually, or only when both eyes are open.
- Check visual acuity in each eye while patient is wearing his or her glasses.
- Check for an afferent pupillary defect by swinging a flashlight from one eye to the other. Compare each pupil’s reaction to light and note any asymmetry.
- If optic neuritis is suspected, check color vision by asking the patient to look at a brightly colored object with each eye and report how vivid the color appears.
- Carefully examine the patient’s eyes in primary position (straight ahead) and in all fields of gaze (right, left, up, and down) for any movement limitation or nystagmus. Examine slow eye movements (pursuit) as well as quick ones (saccades).
- If possible, use an ophthalmoscope to look for optic nerve pallor. “Sometimes a very subtle nystagmus can be discovered at the same time,” said Dr. Shin.
- When in doubt about any visual problem an MS patient may be experiencing, consult a neuro-ophthalmologist.
Helping Patients Make the Most of Medicare Part D

The sweeping changes brought about by the Medicare Modernization Act are well under way. However, some patients, including those with multiple sclerosis (MS), still may be overwhelmed by the number of prescription drug plans available to them under Medicare Part D—a subsidized program administered by private health insurance companies. “As a result, some patients may feel unsure about how to proceed,” said Karen Techner, MAT, Intake Coordinator at the Rocky Mountain MS Center King Adult Day Enrichment Program in Denver.

**Finding a Plan**

Medicare typically covers Social Security retirement recipients over 65. Younger individuals with MS are eligible if Social Security considers them permanently disabled and has provided them with disability benefits for at least 24 months.

Patients who have Medicare-only insurance have until May 15, 2006 to enroll in a plan. (The exception is for those who have creditable coverage, which means that a patient’s present drug coverage is considered to be at least as good as standard Medicare coverage.) If patients miss the deadline, they may be subject to a lifetime premium penalty of an additional 1% per month instead of benefiting from the long-term cost savings that the new drug plan will afford.

Providers should encourage these patients to log onto Medicare’s Web site (www.medicare.gov) to obtain step-by-step instructions for enrollment, Ms. Techner advised. When enrolling, patients should have their Medicare card and a list of their prescribed medications and dosages handy. In choosing a plan, it is important to make sure that the patient’s prescribed drugs are on their specific provider’s formulary. “So far, we’ve found that all of the MS medications are covered by one plan or another,” Ms. Techner added.

Premium payments vary according to formulary options and the patient’s geographic region. Additionally, some Medicare-only patients may qualify for further subsidies. “If the patient is unsure about which option is best, it may be easier for the clinician to review the options and advise the patient on the most cost-effective plan,” Ms. Techner said.

**Dual Eligibility: Overcoming Obstacles**

For patients who qualify for both Medicare and Medicaid (dual eligibility, typically determined by state-devised income guidelines), the process may be somewhat simpler, as they were automatically enrolled into a plan by January 1.

“However, don’t assume that because somebody was [automatically] assigned to a plan that it covers all of his or her medications,” Ms. Techner stressed. The patient may have to be re-enrolled under a more suitable plan. Also, there may be a time lag between automatic or early enrollment and the arrival of a new insurance card, which may cause confusion at the pharmacy when prescriptions are being filled. In these cases, pharmacy staff can use the patient’s old Medicare card to determine his or her new plan.

“Health care providers are busy people,” Ms. Techner acknowledged. As a consequence, referring patients to a national agency or organization for enrollment help and information may be in order (see “Medicare Part D Resources”). She also recommended steering patients towards local or state coalitions and nonprofit organizations for further assistance.

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**Medicare Part D Resources**

For questions on Medicare’s new prescription drug coverage premiums for specific MS therapies, patients can contact the drug manufacturer.

**Avonex® (MS Active Source™):**
(800) 456-2255

**Betaseron® (MS Pathways™):**
(800) 788-1467

**Copaxone® (Shared Solutions®):**
(800) 887-8100

**Novantrone® and Rebif® (MS LifeLines™):**
(877) 447-3243

**Other Resources**

**Medicare**
www.medicare.gov

**National MS Society**
www.nmss.org

**Eldercare Locator**
www.eldercare.gov

**Access to Benefits Coalition**
www.accesstobenefits.org

**Medicare Rights Center**
www.medicarerights.org

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ATAXIA...continued from page 4

MANAGING SYMPTOMS OF ATAXIA

Although any type of ataxia is difficult to treat, there are tips patients can follow to help them compensate for the disorder, according to Wendy Hendrie, MSc, MCSP, head physiotherapist at the MS Therapy Centre in Swaffham, UK. Following are some pointers that she recommends to her patients.

For Intention Tremor in the Upper Limbs

Use single joint movements. “For example, when eating, support the body fully in a chair and lean the elbow on a high table before bringing a utensil to the mouth,” Ms. Hendrie said.

Keep the trunk well supported. Make sure to sit in a sturdy chair with arm supports, if possible. “The arms will shake less if the trunk is stabilized,” Ms. Hendrie explained.

Don’t look directly at an object. “Doing so may worsen tremor,” she said. “Instead, patients should try reaching for objects from different angles to discover if one position results in less tremor.” For example, it may be easier to pick up a drink placed to one side of the body than one placed in front.

Use weights. Wrist weights may help to ease shaking. However, Ms. Hendrie cautions her patients against using very heavy weights, which will fatigue the muscles more quickly and/or worsen tremor.

Cool muscles. “Using an ice pack to cool forearm muscles has been shown to reduce tremor for up to 45 minutes,” she said. This may be particularly helpful before activities such as eating a meal.

For Ataxia of the Lower Limbs

Use a four-wheeled walker. “Doing so can increase walking speed and facilitate daily activities,” said Ms. Hendrie.

Exercise (gently). Yoga, tai chi, and Pilates may be helpful for people in the early stages of ataxia.

such as seizures, has also been reported.

Because pharmacologic agents and surgery rarely yield completely satisfactory long-term results, compensatory and restorative techniques are important for MS patients with CA (sidebar). Clinically, the emphasis has been on compensatory approaches, such as using adaptive aids, making environmental modifications, and learning new strategies.

ADAPTIVE STRATEGIES

Many compensatory aids utilize viscoelastic forces to reduce the effects of tremor. For example, ataxic computer users can attach a device to their mouse that is designed to reduce unsteadiness as they point and click. There is some evidence in the literature that Lycra® garments may facilitate movement for persons with cerebral palsy and other neuromotor deficits, either by dampening tremor or altering sensory feedback.3 This approach is beginning to find favor among persons with MS in the United Kingdom, although clinical studies have not yet been conducted.

Another compensatory strategy is to learn new strategies for performing tasks, such as breaking a large motion down into several smaller movements that involve moving one joint at a time.

Restorative approaches, such as performing exercises that strengthen muscles, may also be helpful. In Europe, the most commonly used approach is rhythmic stabilization, which is intended to improve proximal control, Dr. Marsden said. Another approach is a program of exercises similar to those used for vestibular rehabilitation; however, neither strategy has been formally studied in ataxic MS patients.

CHALLENGES TO TREATMENT

There are several reasons why CA has proven hard to treat in MS patients, Dr. Marsden explained. “First, there is evidence to support the fact that cerebellar lesions cause not only motor symptoms but also cognitive and affective deficits. Therefore, we might be overlooking the fact that some MS patients with cerebellar ataxia also have cognitive and affective problems, which would obviously impact how they function and how well they respond to treatment,” Dr. Marsden noted.

Another hurdle to therapy is that the ability to learn new movements is modulated by the cerebellum. However, if this region has been damaged by MS lesions, learning new movements (or relearning old ones) may present formidable challenges for patients, said Dr. Marsden.

—Peter Doskoch

REFERENCES


MS Exchange February 2006 | 9
The unpredictable course of multiple sclerosis (MS) leaves those affected with an uncertain future. Recent advances in understanding the disease and its treatment have improved the ability of health care professionals to help MS patients and their families. In addition to providing an accurate diagnosis and supportive care, treatment now can be directed toward changing the disease course. As a result, MS nurses worldwide are faced with many challenges as they meet the needs of their patients.

The MS nurse is a competent expert who collaborates with those affected by MS and shares knowledge, strength, and hope. MS nurse specialists have drawn from research, education, and practical experiences to develop a new and cohesive model of nursing care in MS, one which will sustain and educate nurses in their clinical practice, promote nursing research, and inspire a new generation of MS nurses as they enter the field. This model is the leitmotiv of the International Organization of Multiple Sclerosis Nurses (IOMSN), the umbrella organization for a number of multinational MS nursing organizations.

THE IOMSN: DEVELOPING A MODEL FOR MS NURSING PRACTICE

Founded in 1997, the IOMSN has grown from a small corps of MS nurses to over 1,000 members from 27 countries. Over 400 nurses have passed the certification examination for MS nursing, thus earning the title of MS Certified Nurse (MSCN). My, how we have grown!

Nursing practice aims to manage and influence the patient’s illness by supporting disease-modifying treatments; facilitating symptom management; promoting safe and maximal function; and fostering a wellness-oriented quality of life.

Activities that are essential to patient care can be grouped into categories: establishing care; continuing care; and sustaining care. Together, these interwoven areas provide a framework for a comprehensive model for MS nursing practice that can be applied to care of all MS patients, regardless of disease classification or level of disability.

LOOKING TO THE FUTURE

The goals of the IOMSN are to sustain its current level of membership and to expand its impact during the coming years. It is hoped that the specialty of MS nursing will become internationally recognized as a vital component of lifelong MS care. To achieve these goals, the IOMSN has developed and implemented the following programs:

- A mentorship program for MS nurses entering the field
- An advance practice nursing advisory program in both clinical care and research (see page 5)
- An academic outreach to schools of nursing throughout North America and in affiliate countries

In addition, we will continue our existing informational programs:

- MS Exchange and the International Journal of MS Care
- Our official, interactive Web site: www.iomsn.org
- Annual and regional meetings for regular MS nursing updates

The IOMSN welcomes input and suggestions for future programs and ideas to enhance our services to the MS nursing community. We hope to continue our growth and development through the support of our current membership and potential new members.

The long-term goal of the IOMSN is to reclassify MS as a disease with a cure; in the interim, we continue to strive to improve the lives of all those affected by the disease worldwide.
EARLIER DETECTION
OF SPINAL CORD
ATROPHY IN RRMS
Serial upper cervical cord atrophy (UCCA) measurement is useful for detecting the development of spinal cord atrophy early in the disease course of relapsing-remitting MS (RRMS), according to a recent United Kingdom study published in the Journal of Neurology, Neurosurgery, and Psychiatry. Over the course of the three-year investigation, significant UCCA atrophy occurred only in RRMS patients, in contrast to a control group, the authors reported.

Included in the analysis were 19 women and eight men with RRMS, all within three years of symptom onset; median Expanded Disability Status Scale (EDSS) score was 1.0 (range 0 to 3.0). These patients and 20 healthy controls underwent MRI scanning at baseline and annually for up to three years. Changes in UCCA were compared between the groups.

Patients’ rate of UCCA during the study period was significantly faster than that of controls (mean difference per year: −1.161 mm²; P = 0.001). In year 3, the difference in UCCA from baseline between patients and controls reached borderline significance (mean difference: −4.239 mm²; P = 0.074).

During follow-up, patients experienced significant increases in EDSS scores and in brainstem, pyramidal, and bowel and bladder symptom functional scores, though none entered the secondary progressive stage of MS.

Although this was the first study to longitudinally investigate RRMS patients “as early and for as long a period of time,” more study is required to determine whether early cord atrophy predicts future disability due to myelopathy, the authors concluded.


BONE MARROW
TRANSPLANT FAILS
TO SLOW MS PROGRESSION
A recent study from the Netherlands found that a radical immunosuppressive regimen involving total T cell ablation and autologous bone marrow transplantation led to serious adverse effects and did not stave off clinical deterioration in MS patients with secondary progressive disease.

At baseline, the eight women and six men who participated in the study had a rapidly deteriorating disease course but retained the ability to walk. Bone marrow was aspirated from the posterior iliac crest, and T cell ablation was achieved through infusion of antithymocyte globulin and through irradiation. (CD34 purification was used to concentrate stem cells and deplete T cells in the hematopoietic graft.) The autologous graft was reinforced via a central venous catheter. Patients were followed for seven months to three years.

Nine of the 14 patients studied reached the level of treatment failure, defined as rise in EDSS score of 0.5 or more, sustained for at least six months, the researchers from Erasmus Medical Centre in Rotterdam observed. In addition, all posttransplant patients experienced alopecia, loss of dexterity, and general fatigue.

Since other studies on stem cell transplantation in MS patients implementing milder immunosuppressive protocols have yielded better results, “the question arises as to whether the rapid progression seen in our study could be related to the neurotoxicity of the [extreme immunosuppressive] procedure itself,” stated the authors.

Due to the lack of efficacy of this regimen and the serious adverse effects that patients experienced, the researchers do not recommend future studies using similar protocols. MSX

April 1–8, 2006
58th Annual Meeting of the American Academy of Neurology. Location: San Diego, Calif. Contact: AAN Member Services, 1080 Montreal Avenue, St. Paul, MN 55116; (800) 879-1960; fax: (651) 695-2791; e-mail: membership@aan.com; Web site: www.aan.com.

April 22–25, 2006
38th Annual Meeting of the American Association of Neuroscience Nurses. Location: San Diego, Calif. Contact: AANN, 4700 W. Lake Avenue, Glenview IL 60025; (888) 557-2266 (US only); (847) 373-4733; fax: (877) 734-8677; e-mail: info@aann.org; Web site: www.aann.org.

September 2–5, 2006
10th Congress of the European Federation of Neurological Societies. Location: Glasgow, UK. Contact: EFNS Head Office, Breite Gasse 4–8, A-1070 Vienna, Austria; +43 1 889 05 03; fax: +43 1 889 05 03 13; e-mail: headoffice@efns.org; Web site: www.kenes.com/efns2006.

September 27–30, 2006
22nd Congress of the European Committee for Treatment and Research in Multiple Sclerosis. Location: Madrid. Contact: AKM AG, Clarastrasse 57, PO Box CH-4005, Basel, Switzerland; +41 61 686 77 77; fax: +41 61 686 77 88; e-mail: info@akm.ch; Web site: www.akm.ch/ectrims2006.

October 8–11, 2006
131st Annual Meeting of the American Neurological Association. Location: Chicago. Contact: ANA, 5841 Cedar Lake Road, Suite 204, Minneapolis, MN 55416; (952) 545-6284; fax: (952) 545-6073; e-mail: julieratzloff@llmsi.com; Web site: www.aneuroa.org.

CMSC 2006 ANNUAL MEETING
The 2006 Annual Meeting of the Consortium of Multiple Sclerosis Centers will take place May 31 to June 3 at the Westin Kierland Resort in Scottsdale, Arizona. The theme is “Celebrating 20 Years of Excellence in MS Care and Research.” Presentations will pertain to timely issues involving MS patient care and basic and clinical research, as well as those that reflect collaboration between specialties. Go to www.mscare.org for additional information, or contact Tina Trott, Executive Assistant, Consortium of Multiple Sclerosis Centers, c/o Gimbel MS Center, 718 Teaneck Rd, Teaneck, NJ 07666; (201) 837-0727 ext 120; fax: (201) 837-9414; e-mail: tina.trott@mscare.org.

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