



IOMSN Update

Multiple Sclerosis Nursing in 2001: A Global Perspective

MS Nursing Around the World

At the annual Consortium of Multiple Sclerosis Centers (CMSC) meeting in Fort Worth, Tex, May 31 to June 3, many professionals in the field of MS gathered to learn from each other's experiences. The following is a sample of the international presentations.

Indicators of Rheumatic Disease Are Common in People With MS

Researchers from Zapopan, Mexico, found that rheumatic disease indicators and serologic abnormalities are common in individuals with MS. Owing to the broad spectrum of clinical and serologic symptoms that MS may include, the researchers believe that careful evaluation is necessary to avoid a misdiagnosis.

Forty study participants with definite MS (mean disease duration, 10 years) were assessed by two rheumatologists who used physical examination, Schirmer tests, and serologic laboratory studies, such as rheumatoid factor (RF), antinuclear antibodies (ANAs), anticardiolipin (aCL) antibodies, and anti-double-stranded deoxyribonucleic acid (anti-dsDNA) antibodies, to detect the signs and symptoms of rheumatic disease. Eight of the 40 participants—30 of whom were female—had a history of arthri-

tis involving at least two joints, and four of them reported photosensitivity without malar rash. Seventeen people in the group complained of lower back pain, and one had definite sacroiliitis. Only one person met the criteria for fibromyalgia.

When testing was complete, seven participants demonstrated positive Schirmer tests. In the serologic studies, five individuals had positive RF; ANAs were present in another five; and three had aCL antibodies. None of the participants had positive anti-dsDNA. These results led the researchers to conclude that rheumatic manifestations and serologic abnormalities are widespread in people with MS.

Increasing Incidence of MS in Caribbean Countries

Recent observations on the status of MS in Caribbean countries point to an apparently increasing incidence and prevalence higher than was traditionally believed. This data review of current information was undertaken in response to the steadily growing interest in MS in this region of the world.

A study of the distribution of MS in Cuba by Cabrera-Gomez et al showed a prevalence of five to 10 persons per 100,000, though the rate may actually be higher, and prevalence rates appear to differ greatly in places having the same geographical situation. For example, surveys in the

Espartaco Sugar Factory and in Ciego Motero found a prevalence of 150 per 100,000, and 100 per 100,000, respectively.

MS rates were found to be equivalent in both white and nonwhite populations, with symptoms clinically similar to those found in the disease worldwide. However, a primary progressive form of MS is found in Cubans whose ancestors were immigrants from Spain (particularly the Canary Islands and Galicia), France, and England; this clinical form of MS also appears in 15% of Cuban-Americans from the United States whose family histories include the subpopulation of Cubans with both this ancestry and with primary progressive MS.

Jamaican-born persons with MS show no clinical differences in disease experience from that of other countries, according to a report from Cruickshank and Montgomery. The Puerto Rican MS Study Committee found 2,300 clinically definite cases of MS and estimated prevalence at 40 persons per 100,000. Clinical, imaging, evoked potentials, and human lymphocyte antigen studies were similar to those in Europeans with MS; human T-cell lymphotropic virus types I & II were not present. Martinique was found to be a medium-risk zone for MS.

Researchers urged the establishment of MS centers in the Caribbean to promote MS research and to improve

treatment and management of MS in this region. They also suggested organization of national computerized MS registries and databases to record the incidence of genetic, neuropsychologic, and epidemiologic markers of disease and to compare the gelatinase A and B activity in cerebrospinal fluid of Caribbean residents with MS.

Concerns About MS Treatment Reflect Reasons for Discontinuation

A study of persons with MS undertaken by Canadian researchers in Calgary, Alberta, found that concerns voiced by people with MS before the start of treatment were also likely to be the reasons why these individuals chose to discontinue such treatment. This suggests that persons with MS retain the education regarding potential side effects that they receive prior to the initiation of treatment.

Sixty-three people with MS participated in the study; 86% reported fears that treatment would not work, 85% had qualms about increased fatigue, and 81% were apprehensive that treatment would make them feel ill. There were no significant differences found in the treatment groups. Drug effectiveness is a frequent concern both prior to and during treatment; it contributes to an individual's decision to discontinue pharmacotherapy. An increase in MS symptoms—particularly fatigue—and flu-like symptoms such as drug side effects also play a significant role in the discontinuation of MS drug therapy.

The researchers noted that directing nursing support to persons with MS who express anxiety about side effects or treatment results may improve the rate of continuation for pharmacotherapy. This may be especially useful in instances where the benefits of MS pharmacotherapy may not be obvious.

Is Substance Abuse Common Among Persons With MS?

In a recent study, significant alcohol problems were not found to be common among persons with MS. However, the rate of such problems may be slightly higher for females with MS than for the general middle-aged population of women. The study participants included 784 persons with MS who responded to a survey. Their average age was 49 and 78% were female.

Fourteen percent of the participants reported having an alcohol problem, and 7% reported using drugs or medications for non-medical purposes. Less than 10% responded that they thought that they should cut down on their drinking, although 41% of those reporting an alcohol problem were interested in learning how to stop or to reduce their intake. Those more likely to report problems with alcohol or drugs tended to be younger, employed, with less-severe MS symptoms, and had a more recent diagnosis of MS. Also, the one-year prevalence of alcoholism in the study group versus the general middle-aged female population was determined to be 4.5% versus 0.8%, indicating a slightly higher percentage for the females with MS. Alcohol and drug use were related to an increase in symptoms of depression.

The researchers suggest that substance abuse might naturally lessen as persons with MS age and develop more severe symptoms. Although the results of this study do not show significant substance abuse problems among persons with MS, health care professionals should be aware of the possibility of such abuse and be ready to offer intervention help or referral information, if warranted.

Depression in Veterans with MS

Researchers found the prevalence of depression in veterans with MS to be comparable to that in other MS populations, and the prevalence of bipolar disorder to be lower than that in other MS groups. This veterans' sample from the Northwest region of the United States provided a unique grouping of persons with MS given the high proportion of older males (86% male, 20% older than 65).

Veterans with MS were identified by the Consumer Health Information and Performance Set (CHIPS) database, a Veterans Administration-based system that tracks veterans' contact with health care providers. Each of the 453 participants completed survey questions about depression. For each item, they were asked to rate how much a specific problem had "bothered them in the last two weeks."

To measure the prevalence of depression and bipolar disorder in persons with MS, the researchers used ICD-9 diagnostic codes for all three variables. The findings showed that: 1) the prevalence of depression in this veterans' sample was comparable to that reported for other general MS populations; and 2) the prevalence of bipolar disorder was actually lower than in other MS groups, and instead, was comparable to that reported in the general population.

Also of interest was the inconsistency between the rates of depression as reported by the veterans and the CHIPS record of depression diagnoses. More than 64% of veterans having a CHIPS depression record did not report symptoms of a major recent depressive episode. Conversely, 71% of the veterans without any CHIPS depression diagnoses reported having symptoms of a major recent depressive event. It is un-

known whether the CHIPS record or the veterans' survey responses provided the more accurate measure of depression in this sample.

Of concern to the researchers was that suicidal thoughts were common among the veterans who did report depressive episodes. They stressed that

further study is needed to reduce suicidal risk in this veterans' population given the known risk of suicide among persons with MS. MSX

Cetirizine Improves Patient Reactions to Glatiramer Acetate Therapy

Urticarial reactions caused by immunomodulatory therapy were markedly reduced by the use of cetirizine (Zyrtec®) in a recent study. The study involved three persons with MS currently undergoing therapy with glatiramer acetate (Copaxone®). All three persons had urticarial injection site reactions from this therapy and wanted to discontinue it.

Each person was given Zyrtec, an antihistamine, once per day. Improvement in urticaria was evidenced within one week for all participants and continued to show even better responses at the two- to three-week interval. All study participants chose to remain on Copaxone therapy.

Such results are encouraging since injection site reactions are a primary reason for persons with MS to discontinue glatiramer acetate medication. By reducing uncomfortable urticarial reactions, persons with MS may be able to continue their much needed immunomodulatory therapy.

Family Approach to MS Care Yields Favorable Results

A number of studies have already explored the impact that MS can have on an entire family. Nurses are already aware of the influence that a family can have on the health and well-being of a person with MS. In one MS clinic, Diane Lowden, MSc(A), a clinical nurse specialist, was hired to address the various needs of persons with MS and their families. Specifically, Ms. Lowden's role is to help families adjust to MS, to reduce the emotional stress on the family, and to enhance family coping mechanisms.

Ms. Lowden cited several case studies that successfully demonstrated the use of family nursing strategies. One of the studies involved a young woman named Kathy and her mother. Kathy, a person with MS, greatly desired to be independent and to live alone in an apartment. Her mother, very observant of Kathy's condition, wanted her daughter to remain at home. Ms. Lowden had a series of meetings with Kathy and her mother, focusing on Kathy's desire to be in control and how this

could be accomplished while Kathy managed her MS exacerbations. As a result, Kathy first moved into the basement of the family home, and a year later moved out and now lives on her own.

Another case study involved Myriam, age 39, a wife and mother who called the clinic frequently to report in great detail her new MS symptoms and/or the worsening of her existing condition. The calls were often lengthy as she was very anxious about her MS diagnosis and in her ability to remain in the same family role. Ms. Lowden held a number of meetings with Myriam and her husband to discuss the couple's concerns, and to explore different ways that Myriam's family and other community agencies may provide support to help Myriam cope with her day-to-day symptom fluctuations and to reshape her family role as needed.

While these are just two of the case studies cited, Ms. Lowden's experience with family nursing strategies has resulted in reported reductions in anxiety levels, improvements in family coping mechanisms, and in a wider range of family needs being addressed. She stressed that in a chronic illness such as MS, the nurse's main goal is to help the family to adjust and adapt, not necessarily to accept the situation. MSX

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Multiple Sclerosis International Conference 2001

The Multiple Sclerosis International Federation (MSIF) International Conference 2001 will take place September 30 through October 5 in Melbourne, Australia. It is a collaborative effort of the International Organization of MS Nurses (IOMSN) and the

MSIF. The conference sessions will include keynote speakers: Peter A. Schweitzer, United States; Professor Stephen Greysier, United States; Professor Ian McDonald, United Kingdom; Professor Alan J. Thompson, United Kingdom; Frederick W. Foley, PhD, United States; June Halper, MSN, ANP, FAAN, United States; Michael Richard Whitlam, United Kingdom; Colleen Harris, RN, MN, Canada; Eija Eliisa Luoto, RN,

Finland; Marie A. Namey, RN, MSN, United States; Dawn Langdon, United Kingdom; and Terry Kilmister, Australia.

Registrations are being accepted through the beginning of the conference. The Conference Calendar on the last page of this issue contains registration information.

The IOMSN dinner is scheduled for Sunday, September 30 from 7 PM to 11 PM. MSX

Lauding a Legend in MS Nursing Leadership

The Consortium of Multiple Sclerosis Centers (CMSC) inaugurated the presentation of its Lifetime Achievement Award by honoring a legend in MS nursing: June Halper, MSN, ANP, FAAN. "As founder and executive director of both the IOMSN and the Bernard W. Gimbel Multiple Sclerosis Comprehensive Care Center in Teaneck, New Jersey, June has long been recognized for her outstanding leadership in the advancement of specialty MS nursing practice and in the advocacy of improved health care for people with MS," said Marie Namey, BS, MSN, whose pleasure it was to bestow the award.

Ms. Halper expressed her surprise and gratification at being chosen as the recipient, and said, "I accept this award on behalf of my associates at the Gimbel MS Center and at the CMSC, and on behalf of all MS nurses who contribute to the team effort in the fight against MS."

IOMSN Celebrates Proponent of Hope

The IOMSN dinner meeting at the CMSC symposium in Fort Worth, Tex, was the setting for the presentation of the Fourth Annual June Halper Award for Excellence in MS Nursing. This year's honoree, Linda Morgante, RN, MSN, CRRN, is familiar to the IOMSN membership as an authority on the

topic of hope in MS care. She has been an MS nursing specialist since 1986 and is a frequent speaker about the nurse's role in providing psychosocial support for both patients and peers.

Ms. Morgante revealed that she was so astonished when she realized that the award presenters (Kathleen Costello, RN, MS, CRNP, and Barbara Johnson, BSN, RN, CRRN) had said her name, "I don't even remember what they said. I only managed to compose myself enough to say 'thank you,' and to promise to continue with self education, personal growth, and the sharing of information with other MS nurses." She expressed her sincere appreciation for being chosen to receive this honor. MSX



Marie Namey (left) and Linda Morgante (right) at the Consortium of Multiple Sclerosis Centers (CMSC) annual meeting in Fort Worth, Tex. Ms. Morgante, Director of Clinical Services, Maimonides MS Care Center, Brooklyn, NY, was the recipient of the Fourth Annual June Halper Award for Excellence in MS Nursing. Ms. Namey is immediate Past President of the CMSC.