



# IOMSN Update

## Multiple Sclerosis Nursing in 2002: A Global Perspective

### Increased Disease Activity Seen During Transition to Secondary Progressive MS

A prospective, five-year follow-up study of persons with MS showed that the period surrounding the conversion to secondary progressive MS (SPMS) disease is a time of increased clinical inflammatory activity. In this study, individuals in the period of “early secondary progressive” disease had a significantly higher annual exacerbation rate (AER) than did those who remained in relapsing-remitting MS (RRMS). The results support those of earlier findings indicating that the transitional period to SPMS is a time of increased clinical disease activity.

Eighty consecutive persons with a diagnosis of clinically definite MS according to Poser criteria were followed for five years. The researchers made a clinical determination of the clinical form of MS at baseline and at years three and five. At the three-year mark, the participants were divided into two groups: one that remained in RRMS at the end of three years, and one that converted to SPMS during this period. The SPMS group was further divided into two groups: one in which con-

version to SPMS occurred during year two, and one in which conversion occurred during year three.

Disease progression was determined through the Expanded Disability Status Scale (EDSS) and an ambulation index, which were administered every three months. Disease progression was defined as an increase of 1.0 or more EDSS points (or 0.5 points if the EDSS was greater than 6.0), sustained for two consecutive visits (ie, for six months). If the person had an exacerbation, the EDSS scores pre-exacerbation and three months following steroid treatment were used to determine progression. An exacerbation was defined as the presence of a new symptom that lasted more than 48 hours, plus an increase of 1.0 point on the EDSS or the worsening of a previous symptom. The researchers calculated an annual exacerbation rate for years before, during, and after the “year of conversion” to SPMS.

The initial distribution of the clinical MS forms was 76.3% RRMS, 16.3% SPMS, and 7.5% primary progressive MS. During the course of the study, 13 participants (21.3%) changed from RRMS to SPMS (six at year 2 and seven at year 3). In the early SPMS group, the AER was significantly higher than in the RRMS group for each of the three evaluated years, as well as overall (Table). The AER difference between the RRMS and late SPMS groups was significant only for the third year, although a trend toward significance was seen in the first year.

The results showed a significant difference in clinical inflammatory activity during the year of conversion to SPMS—an important finding from a disease management perspective, as well as for research purposes. Neither the use of interferon betas nor the use of steroids for exacerbations appeared to influence the conversion to SPMS. Based on their findings, the researchers suggested calling the time surrounding the interval of progression to SPMS “early secondary progressive multiple sclerosis.” A larger cohort of participants with a prolonged observational time is needed to confirm these results. MSX

Casanova B, Coret F, Valero C, et al. High clinical inflammatory activity prior to the development of secondary progression: a prospective 5-year follow-up study. *Mult Scler*. 2002;8:59-63.

#### AER During the Transition to Secondary Progressive MS

Year	RRMS	AER SPMS	P value
Year 1	0.59	1.23	.01
Year 2*	0.51	1.0	.05
Year 3	0.34	0.76	.05

\*Year 2 signifies the “year of conversion” to SPMS.

AER, annual exacerbation rate; RRMS, relapsing-remitting MS; SPMS, secondary progressive MS.

## Self-care Program May Offer Improvements in MS Management

Persons with MS who participated in a professionally guided self-care program showed improvements in mental health, vitality, and the need for assistance with daily activities, according to a recent report in *Clinical Rehabilitation*. During the program, in which providers discussed self-care strategies based on the persons' own priorities, the individuals with MS maintained a higher level of independence compared with controls over six months.

This single-blind, randomized, controlled trial took place over a period of six months at the Centre for Research in Rehabilitation, Brunel University, West London, United Kingdom. The participants, all with a confirmed diagnosis of MS, were recruited voluntarily through MS organizations. Those randomized to active treatment were invited to participate in a discussion of self-care strategies, supported by a booklet that was developed for the study in line with consumer priorities. The interventions took the form of group or one-on-one sessions, depending on participant preference. Two sessions were conducted over a one-month period, either at the participants' homes or at a local therapy center.

Various physical and psychological scales were used in the assessment, including the Short-Form 36 (SF-36), the Barthel Index (a scale measuring mobility), and the Standard Day Dependency Record (SDDR), a scale that measures the extent to which persons are assisted in activities of daily living, including personal care, mobility, household tasks, leisure, and employment. Assessments were conducted at baseline and after six months.

Overall, 169 of the 183 persons who entered the study completed the protocol. All participants had lower SF-36 scores at baseline than did the general population, with the lowest scores seen on physical functioning measures. Over the course of the study, mobility deteriorated in both groups, but the deterioration was more marked in the control group. Other measures of the SF-36, including mental health, pain, social functioning, and vitality, improved in the intervention group but decreased in the control group. On the SDDR, those in the intervention group showed a reduction in the perceived need for assistance. Analysis of Barthel scores showed that those in the control group deteriorated in their independence over time, whereas those in the intervention group maintained their independence.

"This unique program, which incorporated lay priorities, had statistically significant benefits for a

community population of people with multiple sclerosis," observed the authors. "Participants in the intervention group had significantly better mental health and less fatigue as measured by the SF-36 than did participants in the control group following the intervention." Those in the intervention group "also reported that assistance with daily activities was less essential than it was for individuals in the control group."

The findings of this study are significant for a number of reasons. First, they demonstrate that effective interventions need not be expensive or resource-intensive. The actual interventions here were minimal, consisting merely of two consultations on self-care strategies and a booklet that incorporated consumer priorities. Second, they showed that establishing interventions based on the person's priorities is an effective component of care.

"Many people with MS are frequently left to their own devices when dealing with day-to-day living," said the researchers. When people do obtain advice from their providers, "their priorities and those of professionals are often divergent. Thus, it would seem to be important to recognize the views and priorities of people with MS when giving such advice." MSX

O'Hara L, Cadbury H, DeSouza L, Ide L. Evaluation of the effectiveness of professionally guided self-care for people with multiple sclerosis living in the community: a randomized controlled trial. *Clin Rehabil*. 2002;16:119-128.

## MS Fatigue Is Independent of Inflammation

MS fatigue is unrelated to systemic markers of inflammation, according to a group of researchers from the Institute of Neurology, London. In this analysis of 38 persons with

relapsing-remitting, secondary progressive, and primary progressive disease, fatigue was independent of a number of common markers of inflammatory disease activity, including urinary neopterin excretion, and serum C-reactive protein levels. The results provide further evidence that fatigue is not associated with disease type or the level of disease activity.

The authors of this study hypothesized that higher levels of systemic markers of inflammation would be associated with increased levels of fatigue. They recruited 38 persons with clinically definite MS: 16 relapsing-remitting, nine secondary progressive, and 13 primary progressive. Of the relapsing-remitting individuals, seven were considered to have benign disease, defined as a disease duration of at least 15 years with an Expanded Disability Status Scale score of less than or equal to 3.0. Excluded were those with symptomatic infection or asymptomatic bacterial colonization, which might have the potential to confound inflammatory marker findings.

Fatigue was assessed using the Fatigue Severity Scale (FSS) and the Fatigue Questionnaire Scale (FQS). Because of the reported association between fatigue and depression, mood was also assessed using the Hospital Anxiety and Depression (HAD) scale. Inflammatory markers assessed included levels of urinary neopterin and creatinine, C-reactive protein, and soluble intercellular adhesion molecule-1 (sICAM-1).

No correlation was found between levels of urinary neopterin and creatinine, serum C-reactive protein, or sICAM-1 and either fatigue inventory. Clinically, those with benign disease were as fatigued as those with non-benign disease. Surprisingly, those with primary pro-

gressive disease had lower fatigue scores on the FQS (but not the FSS). There were no differences in the HAD scale scores among the groups.

“The results of this study do not support our primary hypothesis; that is, the levels of proinflammatory markers did not correlate with the levels of fatigue in those with MS,” concluded the researchers, led by Gavin Giovannoni, MD. The “poor association of proinflammatory markers and fatigue in this study,” they noted, is in accordance with findings of other studies showing that inflammatory disease activity on magnetic resonance imaging does not correlate with fatigue. Importantly, the two fatigue scales did not correlate with each other, leading the authors to conclude that additional research is necessary on the assessment of fatigue.

The lower fatigue levels in the primary progressive individuals are intriguing, as primary progressive disease is generally associated with a more insidious onset and lower levels of inflammation. “If inflammation [does] play a role in MS fatigue,” the authors observed, “the lower levels of inflammation within the central nervous system of those with primary progressive disease may explain their lower fatigue scores.”

MSX

Giovannoni G, Thompson AJ, Miller DH, Thompson EJ. Fatigue is not associated with raised inflammatory markers in multiple sclerosis. *Neurology*. 2001;57:676-681.

## MRI: A Valuable Tool for Pediatric MS

A recent study demonstrated the value of magnetic resonance imaging (MRI) in diagnosing MS in children who experience an acute development of neurologic manifestations with early recovery. In this study, MRI helped confirm the diagnosis in 15 children with clinically definite or suspected MS. The results showed that MRI is as valuable a tool in pediatric populations as in adult populations, and can help distinguish those with MS from those with benign, self-limiting neurologic illness.

“The introduction of MRI in children with an initial diagnosis of acute disseminated encephalomyelitis established new possibilities for making the diagnosis and predicting the clinical course of the disease in these individuals,” said the researchers, from the University Hospital of Neurology, Sofia, Bulgaria.

This study included 25 children (ages three to 18 years), 10 of whom had a diagnosis of clinically definite or

laboratory-supported MS, according to Poser criteria. The remaining 15 had a diagnosis of suspected MS. In addition to repeated neurologic examinations, MRI was conducted in all participants with definite MS and in five of the 15 with probable MS.

Cerebral MRI disclosed multifocal hyperintense MS-like lesions on T2-weighted imaging in all 10 of the children with a diagnosis of definite MS and three of the five with suspected MS. Follow-up MRI showed a reduction in lesion size in three of the 10 children with definite MS and enlargement of the lesions in the remaining seven. In four participants, the lesions persisted for a “considerable period after normalization of the neurologic signs.”

These results “support the opinion that there are no qualitative differences between childhood and adult multiple sclerosis,” said the researchers. “The abnormalities found in all of our cases with definite multiple sclerosis correspond to the recognized criteria in the literature.”

The results provide valuable insight into the diagnosis of pediatric MS, which remains rarely reported

in the literature. To date, there are only 49 published cases of MS in children under six years of age, and seven cases in children under two. The MRI findings, the authors observed, corresponded to a comparatively rapid development of the disease in the children with

clinically definite MS, with four of the children having more than one attack per year and one advancing to secondary progressive disease following the second attack. This rapid disease development, they speculated, may be due to "myelin immaturity at an earlier age, as

well as the more violent immune reactivity of the childhood brain being affected by autoimmune demyelination." MSX

Belopitova L, Guerguelcheva V, Bojinova V. Definite and suspected multiple sclerosis in children: long-term follow-up and magnetic resonance imaging findings. *J Child Neurol.* 2001;16:317-324.



## IOMSN Board Member Receives Award

Colleen Murphy Miller, BS, MS, DNS, received the 2002 State University of New York at Buffalo Alumni of Distinction Award for her contributions to research, education, neurological care, and international leadership in the study of multiple sclerosis on April 19, 2002.

Dr. Miller, who has served on the board of the IOMSN since its inception, is a nurse practitioner at the William C. Baird MS Research Center, which is part of the Jacobs Neurological Institute at the Buffalo General Hospital in New York. MSX

### *A Message From the IOMSN Board*

*We are so proud that the IOMSN is an international organization. Our dues, however, are paid in U.S. dollars. Thirty-five dollars is very reasonable to those of us living in the U.S. and not a hardship for most. For nurses in other countries, that is not always the case. Because our dollar is worth so much more than their currency, paying IOMSN dues is of-*

*ten difficult. It would be a real gesture of friendship and support if those of us who can spare more would add an extra amount to our dues when we pay them. We could then help nurses in other countries afford to join the IOMSN. Please add a gift and a note saying that it is to be used to help another nurse when you pay your dues. Thank you.*

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