



Multiple Sclerosis Nursing in 2004: A Global Perspective

IOMSN Welcomes New Affiliate Member

On behalf of the Board of Directors of the International Organization of Multiple Sclerosis Nurses, it is my pleasure to welcome the Swedish MS Nurses Association (SMSF) as an affiliate organization of the IOMSN. The application that was sent by the SMSF was outstanding and the Board's decision was unanimous. Anna Osterlund was recently elected to represent SMSF as the IOMSN Board representative.

The SMSF applied for affiliate membership for several reasons, which included increasing networking and collaboration between Swedish nurses and nurses worldwide; increasing exchange of clinical

and research information/knowledge within the MS nursing area; facilitating access to support and educational materials for patients and health care professionals; and increasing interest among Swedish

nurses (see sidebar) are clearly in concert with the goals of the IOMSN. In addition, their mission statement joins an evidence-based foundation with the vast amount of experience found in MS nursing.

The IOMSN looks forward to a long, collaborative relationship with the SMSF as we strive to improve the lives of all those affected by multiple sclerosis.

nurses for taking the Multiple Sclerosis Nursing International Certification Examination. The organization's stated mission is to "work and develop our achievements according to evidence-based nursing and long-term experience with the aim to optimize health and quality of life among people with multiple sclerosis."

The long-term goals of the orga-

To become a member of the SMSF, the person must be a licensed nurse with a Swedish nursing registration; meet people with MS in his or her professional and clinical practice and/or perform research in MS nursing; and pay an annual membership fee. For further information about the SMSF, contact: Swedish MS Nurses Association, Attn: Anna Osterlund, MS Center, Dept of Neurology R54, Huddinge University Hospital, SE-14186, Stockholm, Sweden; +46-8-585 822 44; e-mail: anna.osterlund@neurotec.ki.se.

The IOMSN looks forward to a long, collaborative relationship with the SMSF as we strive to meet our mutual goal of improving the lives of all those affected by multiple sclerosis.

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—*Kathleen Costello,*
RN, MS, CRNP, MSCN
President, IOMSN

LONG-TERM GOALS OF THE SWEDISH MS NURSES ASSOCIATION

- Describe and emphasize the role of the MS nurse in health care among people with MS in Sweden
- Facilitate the development of the MS nurse's role in Sweden
- Increase the quality of nursing care in Sweden
- Provide knowledge about MS and nursing care in MS
- Establish/develop and continuously update standards for nursing care in MS
- Serve as a forum for MS nurses in education, support, and the exchange of knowledge and experience in the MS nursing area

Postpartum Social Support Needs of Mothers With MS

The effects of pregnancy on MS have attracted research interest in recent years, with some women reporting relief of symptoms during pregnancy. In contrast, the postpartum period seems to pose particular challenges for mothers with MS. “Studies have shown¹ that exacerbations tend to double during the first three postpartum months and somewhat less than double during the next few months as compared with the year before pregnancy,” said Elsie E. Gulick, PhD, RN, FAAN. In addition, the increased levels of fatigue and postpartum depression experienced by mothers in the general population during the postpartum period are compounded in women with MS, she noted.

Dr. Gulick, Professor Emeritus at the College of Nursing at Rutgers University in Newark, New Jersey, examined the first-year postpartum social support needs of mothers with MS using outcome measures that included the Postpartum Support Questionnaire, the MS-Related Symptom Scale, and personal telephone interviews.

The First Six Months

The first half of the study looked at the social support needs of 175 mothers during the first six postpartum months. The women were assessed at one, three, and six months. “Social support is multidimensional and includes provisions for emotional, instrumental, and informational support,” explained Dr. Gulick.

In terms of emotional support—which involves providing empathy, caring, love, and trust—the mothers reported that they needed to have time for relationships with friends and other interests; to be reassured of their worth and their competency in the mothering role; to feel appreciated; to have others recognize that they themselves needed help either for the infant or various household duties; and to have people talk to them and listen to them.

When it came to instrumental support (help with infant/child care and household tasks), the women reported the need for help with

laundry, cooking, cleaning, and caring for the baby. “They said they desired this help in order to get uninterrupted periods of rest and also to prevent excessive fatigue,” reported Dr. Gulick.

The mothers also required information about caring for themselves, birth control methods, and managing infant care, “especially with respect to the baby’s behavior, crying, sleeping patterns, and ways of comforting the infant,” noted Dr. Gulick (see Table). “Not surprisingly, I found that first-time mothers with MS needed more information than mothers with the disease who had already been down that road before.”

The mothers who had what they perceived as adequate emotional support had significantly fewer prob-

POSTPARTUM CONCERNS OF MOTHERS WITH MS

Concerns About Self

- Increased fatigue
- Emotional distress (anxiety, depression, loneliness)
- Inadequate sleep and rest
- Partner's lack of understanding of mother's condition
- Insufficient help with infant care and household tasks
- Difficulty in organizing daily routines
- Pressures arising from numerous visitors
- Lack of time for herself
- Challenged self-confidence in mothering
- Ambivalence about returning to work
- Losing weight but maintaining good nutrition
- Increase in MS-related symptoms

Concerns Regarding the Infant

- Feeding frequency
- Breast-feeding (nipple problems, sufficient milk, formula supplementation, presence of jaundice)
- Behavior (colicky, fussy, day-night awake/sleep pattern mixed-up)
- Adjustment to siblings
- Regressive sibling behavior (bed-wetting, need for more attention)
- Rate of weight gain
- Health concerns (rashes, respiratory infections, constipation, allergy, gastric reflux, thrush)
- Special needs of premature and multiple birth babies

Source: Gulick EE. CMSC Web site. 2002.²

lems with emotional distress (defined as anxiety, depression, and loneliness), said Dr. Gulick. “Notably,” she added, “the mothers who had higher levels of instrumental support had significantly lower levels of emotional distress during the entire six months.”

MS Symptoms During the First Six Months

Mothers who had increased emotional distress during the first postpartum month also had high levels of fatigue, sensory symptoms such as numbness, and brain stem symptoms like double vision or blurred vision, related Dr. Gulick. At three months, mothers who had increased emotional distress also reported an increase in elimination-related problems and brain stem symptoms. At six months, those who were more emotionally distressed had more brain stem symptoms.

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“Usually, when women have babies, people come and help for the first month or two, and then tend to pull back their support,” noted Dr. Gulick. “Emotionally, physiologically, and socially, mothers in the general population—particularly those with MS—require ongoing support. The infant is growing and developing and becoming more active and demanding, while the mother may be sleeping less,” she said. “Some of these mothers went back to work, so they had to worry about finding proper child care and taking care of the baby as well as their partners.”

The Second Six Months

In the second half of the study, 172 of the mothers participated and assessments were performed at nine and 12 months. Nine-month data were similar to that gathered at 12 months, she said. The mothers who had higher instrumental and emotional support also re-

ported lower levels of various MS symptoms, which included sensory symptoms such as pins and needles, motor symptoms such as arm or leg weakness or falling, brain stem symptoms, elimination problems, and fatigue, she said.

“In the presence of higher levels of social support, the mothers were able to function better in relation to activities of daily living,” noted Dr. Gulick. “Attention to personal care improved, as did the quality of interaction with friends and family and intimacy with their partners,” she added.

“Social support for mothers with MS is truly needed during the whole year following birth. However, the support has to be given at the right time,” Dr. Gulick cautioned. Some mothers reported that they received support but it didn’t come when they needed it. “A few mothers indicated that they received too much support and they weren’t allowed to do the things they wanted to do for the baby,” she added.

Postpartum Relapses

Dr. Gulick found that mothers whose pregnancies were relatively uneventful (no relapses) tended to do quite well during the postpartum period. However, mothers who had troublesome pregnancies with relapses or increased symptoms tended to relapse not only during the

three months following delivery but during the second six-month period as well.

In a previous study, Dr. Gulick found that mothers who breast-fed had fewer relapses than mothers who did not.³ “Quite a number of mothers tell me that when they stop breast-feeding some of their symptoms start to worsen,” she remarked. “However, I wouldn’t recommend breast-feeding for mothers with MS who had troublesome pregnancies. They should consider starting or resuming disease-modifying therapy because of their increased tendency to relapse,” she cautioned.

What can clinicians do to better address the postpartum needs of women with MS? “Health care providers must be alert to the potential difficulties these mothers may experience and provide counseling for them and their partners, or refer them to other relevant services that can provide appropriate support,” stressed Dr. Gulick. “In addition, clinicians can inquire

about the need and availability of social support for the mother during the prenatal period and discuss the specific kinds of support that will likely be needed during the postpartum period.”

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—Rosalee L. Blumer

REFERENCES

1. Confavreux C, Hutchinson M, Hours MM, et al. Rate of pregnancy-related relapse in multiple sclerosis. *N Engl J Med.* 1998;339:285-291.
2. Gulick EE. Postpartum social support needs of mothers with multiple sclerosis. CMSC Professional Discussion Board. [CMSC Web site]. November 20, 2002. Available at: www.ms-care.org/forums/viewtopic.php?t=56. Accessed December 2003.
3. Gulick EE, Halper J. Influence of infant feeding method on postpartum relapse of mothers with MS. *Int J MS Care.* 2002;4:183-191.

The Clinical Care Committee Requests Input for New MS Certification Exam

The Clinical Care Committee of the CMSC is moving forward on an initiative to create a certification examination for multiple sclerosis specialists. Any licensed professional involved in MS care is eligible to take the exam. The exam will be computer based. The first exam is scheduled for August 14–28.

The committee needs your help in creating the exam. We need a large bank of multiple choice questions in several selected areas of comprehensive care. The questions should be evidence-based and be constructed to have only one correct answer. The selected areas include:

1. Fundamentals of multiple sclerosis
 - a. Pathophysiology

- b. Etiology and epidemiology
2. Diagnosis of MS
 - a. Criteria
 - b. Presenting symptoms
 - c. Diagnostic testing
 - d. Natural history and clinical course
3. Multidisciplinary management of MS
 - a. Relapses, disease-modifying therapies
 - b. Symptom management—fatigue, pain, spasticity, tremor, weakness, altered mobility, visual impairment, cognitive impairment, elimination dysfunction
 - c. Health maintenance—wellness strategies, preventing complications
 - d. Psychosocial issues—emotional and cognitive issues, vocational issues, family and cultural issues, abuse and neglect, end of life issues
 - e. Complementary and alternative medicine
4. Patient empowerment
 - a. Advocacy—patient rights, negotiating systems
 - b. Patient and family education—disease specific, goal setting, community resources, legal issues, advanced directives, clinical research

Please e-mail your exam questions to Sallyann Henry at the Professional Testing Corporation: shenry@ptcny.com.

Thank you in advance for agreeing to be a part of this exciting new initiative. We need your questions as soon as possible and will continue to accept them on an ongoing basis to ensure a large and fresh pool of questions.

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—Colleen Harris, RN, BN, MN
Chair of Clinical Care Committee of the CMSC

INTERESTED IN SHARING YOUR KNOWLEDGE WITH THE WORLD? JOIN THE IOMSN!

The IOMSN is the only organization dedicated to the education of MS nurses around the world. If you wish to join the IOMSN, you can access it on the World Wide Web at www.iomsn.org, or contact the organization at:

IOMSN

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