



## Multiple Sclerosis Nursing in 2002: A Global Perspective

### Meeting Highlights

The annual meeting of the Consortium of Multiple Sclerosis Centers (CMSC) took place this year in Chicago from June 5 to 9. The following sections review a variety of international presentations.

#### Pilot Study of Ask-the-Nurse Information Line

A presentation by Deena Lisak, RN, MA, Connie Nesbary, MA, LPC, LLP, and Rose Taylor detailed an Ask-the-Nurse pilot study. Initiated at the Michigan chapter of the National Multiple Sclerosis Society (NMSS-MI), which serves over 15,000 clients with MS, the purposes of the study were to assess the needs of clients of the NMSS-MI chapter, to use the data for program and material planning, to confirm the need for such a program, and to assess whether the program would be replicable in other NMSS chapters.

Phone calls were tracked for 10 months, from July 2001 through April 2002, and call issues were derived from clients and from questions asked at a large ambulatory MS clinic at the University of Calgary, a study of which was presented at the CMSC meeting in June 2001. Typically, when calling, individuals leave their name, phone number, and

medical question on voice mail at a toll-free number. The NMSS volunteer nurse is available one day per week to return calls, and all contacts are recorded with the reason(s) for the call, diagnosis date, caller address, phone number, county, and response to client. For this study, each issue presented during the calls was recorded rather than the number of actual calls. Follow-up calls were made by the volunteer nurse as needed, but were not tracked. Percentages were used to compare issues addressed during the contacts.

During the 10-month period, the NMSS volunteer nurse handled a total of 433 calls. Eighteen percent of the callers asked about disease-modifying medications and 12% asked questions about other medications. The next highest percentage of inquiries dealt with neurologic and non-neurologic referrals, symptom management, and other MS issues; all of these were at 9%. The remaining issues addressed were psychosocial (6%), newly diagnosed cases and research (5% each), MRI (4%), chemotherapeutic agents, intravenous methylprednisolone, complementary and alternative medicine, and equipment (3% each), and calls from professionals (1%). Additional issues to consider recording are insurance, employment, and in-

formational literature. Some issues, such as symptom management, may be broken down into specific symptoms addressed (such as fatigue, pain, vision problems, etc).

The average call was 30 minutes in duration, with some as long as 90 minutes, although time was not documented. Individuals seemed to need someone to listen to them, to discuss issues in detail, and to receive factual materials by mail. They also seemed to want objective information to relieve their concerns, and referrals were made as needed.

Based upon the number of calls (an average of 11 per week) and the variety of issues addressed, the authors concluded that there is a need among people with MS for this type of service and that this program could easily be replicated in other NMSS chapter offices. Further studies could be done on the differences and similarities among chapter programs, based upon calls made to individual MS clinics. The authors also suggested that MS clinics may want to consider replicating the Calgary study.

The results of this study are being used in program planning for the NMSS-Michigan chapter. An evaluation of the program, which may include a qualitative assessment of the reduction of anxiety, is under way.

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## A Brief Assessment Tool for the Hospitalized Person With MS

According to Nancy Eckert, RN, BA, CSG, of the Multiple Sclerosis (MS) Centre of Lehigh Valley Hospital and Health Network in Allentown, Pennsylvania, it is imperative that the bedside nurse have readily available tools to assess the complex needs of the hospitalized person with MS. Toward that end, Ms. Eckert and her colleagues presented a nursing assessment for such individuals. Since those with MS who are hospitalized for surgical or medical procedures as well as for MS care have chronic health issues that require special consideration, obtaining a detailed profile that specifically addresses MS symptoms, symptom management, medications, treatments, and impact on activities of daily living is critical to understanding how these people are affected by the disease. These issues often are underserved by generic admission forms. Integration of this additional information facilitates the multidisciplinary planning that maintains the delicate balance that the individual with MS requires to stay as independent as possible.

The brief assessment tool allows nurses to extract information pertinent to the individual with MS and serves as a guide to help identify the special needs of this complex population. Access to an MS nurse clinician provides an opportunity to:

- Examine the needs of the person;
- Develop a specific tool to look at individual MS client needs;
- Formulate an interdisciplinary plan of care;
- Maximize and maintain a person's independence;
- Identify and anticipate triggers that would provoke an MS exacerbation;

- Anticipate postsurgical needs via rehabilitation;
- Coordinate and access necessary services spanning the continuum of care; and
- Educate health care professionals regarding MS symptom management and the effects of a hospital stay.

Some of the clinically relevant findings that a nurse may identify using the assessment tool include: mobility issues; transfers and gait training; appropriate assistive devices; bowel and bladder management; awareness of temperature sensitivity and control of the hospital environment; associated individual needs related to interferon therapy versus postoperative febrile states; assistance with the activities of daily living; pain management; monitoring for exacerbation of MS symptoms; identification of strategies to prevent stress and fatigue; knowledge deficit of staff and allied health providers of MS symptoms, disease course, and management; the need for maintenance of MS symptom therapy without interruption; and the potential for miscommunication among members of the health care team (Figure).

The plan of care includes identifying gaps in the present admission assessment tool, developing a specific MS assessment tool, and acknowledging the need for a knowledge base that reflects evidence-based practice. Such a plan would provide a better understanding of individual needs, improve quality of care, and promote self-management and independence. In addition, it would maintain a person's locus of control, minimize the length of time an individual is hospitalized, and would return a person to his or her optimal level of individual function.

Utilization of an assessment tool focused on the individual with MS allows that person to have an influence on the course of care while hospitalized and ensures continuity of care. Communication is facilitated by the MS nurse clinician, ensuring that all those involved in care have an adequate understanding of the person behind the disease. For these reasons and others, Ms. Eckert and colleagues concluded that the MS nurse clinician is a powerful resource for staff and physicians in planning and developing an effective plan of care.

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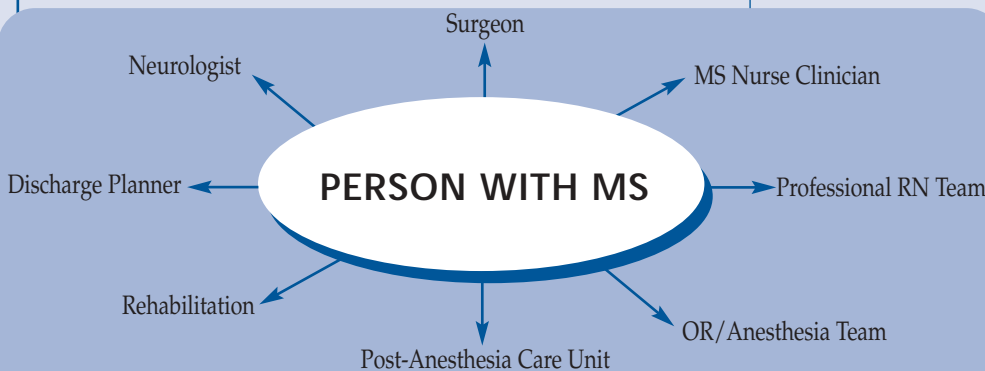


FIGURE. THE MS HEALTH CARE TEAM

## Does Training MS Nurse Specialists Impact the Quality of Life of a Person With MS?

A poster presentation jointly sponsored by the Italian Multiple Sclerosis (MS) Society and the Cleveland Clinic Foundation examined the issue of whether MS nurse specialists affect the quality of life of an individual with MS. The study took place in Italy, where there are an estimated 50,000 people with MS, 20,000 to 25,000 of whom are followed in MS clinics. According to the researchers, nurses working in these clinics typically have no special knowledge or training in MS. The Italian MS Society conducted the study to assess whether the availability of a nurse with specific MS training meets the educational and ongoing care needs of those with MS and influences their quality of life. The study is part of a three-year initiative aimed at creating MS nurse specialists.

Ten nurses from MS clinics throughout the country participated in an intensive five-day training course or-

**TABLE 1**

DEMOGRAPHIC & DISEASE CHARACTERISTICS	GROUP I (n = 93)	GROUP II (n = 86)
Age		
Mean	40	38
Range	21-72	24-66
SD	11	10
Gender		
Female	63 (68%)	60 (70%)
Male	30 (32%)	26 (30%)
Civil Status		
Single	31 (33%)	34 (40%)
Married	54 (58%)	44 (51%)
Divorced/widowed	8 (9%)	8 (9%)
Employment Status		
Employed	55 (59%)	42 (49%)
Unemployed	38 (41%)	44 (51%)
Years Since Symptom Onset		
Mean	10.10	9.86
Range	1-46	1-40
SD	8.94	7.56
EDSS		
Mean	2.5	3.2
Range	0-7.5	0-8.0
SD	1.8	2.0

**TABLE 2**

GROUP COMPARISON ON TIME 0 SF-36	GROUP I (n = 93)	GROUP II (n = 86)	SIGNIFICANCE
Physical Functioning			
Mean	.68	.60	
SD	.44	.30	N/S
Physical Role			
Mean	.46	.48	
SD	.43	.41	N/S
Bodily Pain			
Mean	.62	.67	
SD	.28	.28	N/S
General Health			
Mean	.51	.50	
SD	.22	.24	N/S
Vitality			
Mean	.49	.49	
SD	.22	.21	N/S
Social Functioning			
Mean	.75	.63	
SD	.77	.21	N/S
Emotional Role			
Mean	.70	.54	
SD	.91	.41	N/S
Mental Health			
Mean	.60	.61	
SD	.22	.22	N/S

ganized by the Italian MS Society and completed an examination at the end of the course.

Following the training course, nurses recruited two groups of subjects. Group I consisted of the first 10 consecutive individuals who came to the MS clinic. They received a brochure introducing the option of meeting with an MS nurse, along with the nurse's telephone number and appointment possibilities, a needs questionnaire, the Short-Form 36 Health Survey (SF-36), and a consent form. Group II consisted of the next 10 consecutive individuals; they received the same questionnaire and brochure as Group I. In addition, Group II also received a monthly phone call reminding each person that a nurse was available to discuss the topics listed in the brochure.

The nurse completed a demographic form, and a contact record form for each person was kept for six

**TABLE 3**

GROUP I COMPARISON ON TIME 0 AND TIME 1 SF-36	TIME 0	TIME 1	SIGNIFICANCE
Physical Functioning			
Mean	.65	.65	
SD	.31	.32	N/S
Physical Role			
Mean	.47	.50	
SD	.45	.42	N/S
Bodily Pain			
Mean	.64	.60	
SD	.29	.26	N/S
General Health			
Mean	.51	.48	
SD	.22	.23	N/S
Vitality			
Mean	.49	.46	
SD	.22	.22	N/S
Social Functioning			
Mean	.64	.88	
SD	.23	1.13	N/S
Emotional Role			
Mean	.56	.93	
SD	.45	1.35	.034
Mental Health			
Mean	.60	.59	
SD	.22	.22	N/S

Table 2 shows a comparison between groups on baseline SF-36. There was no significant difference on any subscale of the SF-36.

Table 3 compares SF-36 at Time 0 and Time 1 on 57 subjects from Group I who have completed two assessments by this report. A significant improvement was seen on the subscale emotional role ( $P = .034$ ). There were no other significant differences.

This interim analysis indicates that individuals who participated in the MS nurse specialist program experienced an immediate benefit in their emotional well-being. Even with this positive outcome, the current data do not provide sufficient indication of the overall benefit of this program. Complete data will allow the researchers to understand the overall benefit of this training program for individuals with MS.

In addition to SF-36 results, the final analysis will indicate the extent to which people with MS believed their needs were met following the implementation of the nurse training program.

One limitation of this study is the use of the generic SF-36 to assess the benefit of this program to those with MS. Use of disease-specific measures may have provided better information, but these were thought to create a burden for the individuals in the project. Because this was a pilot study, the researchers thought it was important to maximize information obtained from the evaluation of the program, while minimizing responder burden.

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months. The needs questionnaire and SF-36 were repeated at six-month intervals.

Nine out of 10 nurses passed the examination with a score of greater than 80%, which was the preestablished cutoff point. The same number of nurses also completed subject enrollment. A total of 179 individuals participated in the study.

Table 1 shows the demographic and disease characteristics for both groups. There was no significant difference between groups on age, gender distribution, years since symptom onset, and the Expanded Disability Status Scale (EDSS). Although a higher percentage of subjects in Group I were employed and married, the difference was not significant.

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