



Multiple Sclerosis Nursing in 2003: A Global Perspective

Meeting Highlights

The annual meeting of the Consortium of Multiple Sclerosis Centers (CMSC) took place this year in San Diego from May 28 to June 1. The conference represented a collaborative effort by the CMSC, the International Organization of Multiple Sclerosis Nurses (IOMSN), and the Latin American Committee for Treatment and Research in Multiple Sclerosis (LACTRIMS).

"This year, the meeting was larger and busier than ever," said June Halper, MSCN, ANP, FAAN, Executive Director of the CMSC and the Bernard W. Gimbel Multiple Sclerosis Comprehensive Care Center in Teaneck, New Jersey. There were approximately 850 attendees at the conference.

"We had more symposia, more scientific papers, and more posters than any previous year," noted Ms. Halper. Highlights included presentations on symptom management, interdisciplinary approaches to care, cerebral spinal fluid analysis, and the use of magnetic resonance imaging (MRI) in clinical practice.

During opening ceremonies, CMSC President Frederick W. Foley, PhD announced the launch of the organizational phase of the MS Coop-

erative Studies Group Research Initiative—a steering committee formed to address the need for a coordinated and sustainable infrastructure for cooperative MS research.

The initiative is intended to encompass a broad spectrum of researchers, MS centers, and patients, he explained. He expressed hope and excitement regarding the initiative and its stated mission of identifying and conducting "high-quality research that will further the understanding of MS and its effects, reduce disease activity, and advance therapeutics in order to improve the quality of life of MS patients."

LACTRIMS—CMSC's Latin American Affiliate

LACTRIMS' significant participation in the meeting emphasized the international flavor of the conference. A day-long Latino track offered in Spanish and Portuguese addressed issues such as epidemiology, clinical characterizations, and new avenues of research in Latin America.

"For the first time, LACTRIMS members will speak at length and contribute to various workshops," said Victor Rivera, MD, President of LACTRIMS, during his lecture on Latin American epidemiology.

"LACTRIMS' affiliation with the CMSC is a wonderful example of

international communication and education," he remarked. "As our association matures, we feel privileged to be part of this international effort."

LACTRIMS was formed by neurologists from 21 countries to address the challenges posed by MS as the disease has become more prevalent in Latin American regions, said Dr. Rivera. The organization was founded during the Pan-American Congress of Neurology in Cartegena, Colombia in 1999.

Since LACTRIMS' inception, the CMSC has played a significant role in the organization's meetings, he noted.



The CMSC was formed in 1986. "Our impact has reached throughout the world," said Ms. Halper. "We have collaborated with numerous organizations to meet our goals and provide the highest standard of care for people with MS." **MSX**

—Rosalee L. Blumer

Optimizing MS Patient Care: A Nursing Approach

The introduction of disease-modifying therapies (DMTs) for MS over the past decade has had a significant impact on the care of those living with the disease. Initially, the nurse's focus was on ensuring adherence to therapy by managing drug-related adverse events. However, this is only one factor in achieving optimal outcomes in patients using DMTs. For this reason, the North American MS Nurses' Treatment Optimization Group, which consists of 80 MS nurses from Canada and the United States, convened in October 2002. The group's focus was to develop an evidence-based resource outlining nursing strategies to address potential problems affecting MS patients' overall health status. The result of their extensive work is the Nursing Approach shown in the Figure on page 7.

For each step in this approach, the group developed dynamic care plans that outline assessment strategies, optimal order and timing of interventions, desired patient outcomes, and evaluation methods. They presented their findings in a poster at the recent CMSC conference in San Diego.

Step 1: Initial Assessment and Patient Selection

The process of long-term treatment optimization begins with a thorough clinical, MRI, and psychosocial assessment of the patient to ensure that he or she is an appropriate candidate for DMT and is ready to initiate treatment.

Even if the patient is not yet ready to start therapy, an individualized care plan should be developed in collaboration with the patient and family. This plan should be responsive to the changing needs and level of readiness of both the patient and loved ones. By ensuring treatment readiness prior to therapy selection, the nurse increases the likelihood of optimizing treatment at a later stage.

Interventions for treatment readiness

- Implement strategies to address physical/cognitive deficits that may impact treatment decisions and refer to appropriate health care professional
- Validate fears and modify impression that MS is "untreatable"

- Tailor and provide education on disease and treatment options according to patient's readiness
- Ensure optimal support networks are available and mobilize patient resources

Desired patient/family outcomes

- Understand the importance of therapy and personal barriers to treatment
- Express readiness to start treatment
- Incorporate plan into everyday lives and commit to the plan in the long term
- Demonstrate possible health-promoting and coping behaviors

Step 2: Treatment Selection

Because sustained treatment with DMTs in people with relapsing-remitting MS (RRMS) has been associated with several positive outcomes, Canadian and international guidelines emphasize the need to start treatment with these agents early in the disease course.

As the primary patient educator, the nurse plays a paramount role in ensuring the patient receives the most effective treatment possible based on his or her individual needs. Choosing the most effective treatment from the outset will help ensure optimal patient outcomes in the long-term.

For best results, the patient should continue treatment as long as benefit is realized and therapy is tolerated. However, the process of treatment selection is not simple because the DMTs differ in their mode of preparation, dosage level, adverse-event profile, route of administration, and proven efficacy on patient outcome measures such as relapse rate, disease progression, and MRI readings.

Interventions for optimal treatment selection

- Provide patient with reliable information regarding treatment efficacy and adverse-event profile
- Ensure patient and family participate fully in the decision-making process

Desired patient outcomes

- Makes informed decision regarding treatment
- Most effective therapy is chosen based on individual needs and resources
- Therapeutic regimen corresponds with lifestyle and cultural values

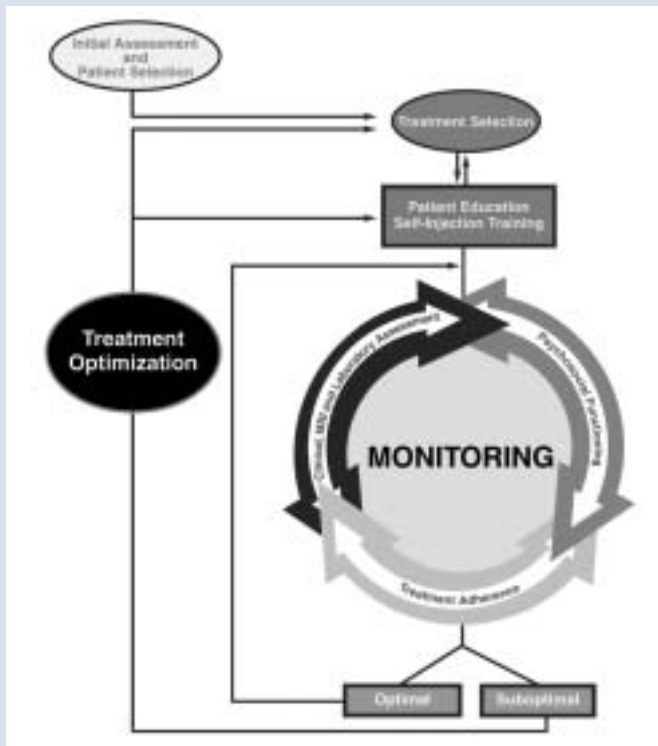


Figure. Nursing approach to long-term treatment optimization in individuals with MS using DMTs.

The North American MS Nurses' Treatment Optimization Group developed an evidence-based nursing approach to address the many factors involved in obtaining optimal patient outcomes.

Step 3: Patient Education and Self-Injection Training

The primary goal of patient education is to empower patients to take responsibility for managing their disease.

Since DMTs are currently only available in injectable form, the introduction of these therapies requires extensive patient and family education on appropriate self-injection techniques—site selection, rotation, and injection-site management—and the management of treatment-related adverse events. Ensuring that the patient self-injects appropriately and successfully manages adverse events and injection-site reactions will help promote optimal therapeutic outcomes.

Interventions for patient education and self-injection training

- Educate and prepare patient for possible flu-like symptoms (for interferon-beta therapy) or immediate postinjection reactions (for glatiramer acetate) as well as other possible adverse events

- Implement nonpharmacologic and pharmacologic strategies
- Reinforce appropriate management of adverse events at each visit

Desired patient outcomes

- Patient reports adverse events in a timely fashion and manages them appropriately
- Patient times administration of medication in order to minimize adverse events
- Systemic adverse events are minimized

Step 4: Long-Term Assessment and Monitoring

Central to the Nursing Approach is the regular and long-term clinical, MRI, and laboratory assessment of the patient (including the assessment of physical and cognitive functioning), the evaluation of psychosocial functioning, and the monitoring of adherence to therapy. It should be emphasized that these assessments are interrelated (as depicted in the Figure). Poor outcomes on one of these parameters may have an effect on the others. Suboptimal clinical, MRI, psychosocial, or adherence outcomes may require re-education, additional assessments, interventions designed to optimize functioning and, in some cases, a reconsideration of treatment choice.

The primary goal in this step of the Nursing Approach is to ensure that the patient follows an effective treatment regimen so the best possible physical, psychosocial, and quality-of-life outcomes are achieved.

Interventions for suboptimal adherence

- Inform neurologist if nonadherence is due to suboptimal treatment response and collaborate with neurologist and patient to determine if switching therapy is necessary
- Ensure patient maintains realistic expectations for treatment
- Assist patient in obtaining funding for therapy

Desired patient outcomes

- Patient adheres to treatment regimen
- Patient feels sense of control over MS
- Patient and family experience an improvement in quality of life
- Decrease in the number of complications associated with the disease

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Developing Patient Education Materials: The Experience at the Calgary MS Clinic

It is vital for clinicians to stay aware of the changing needs of the MS population and to continue to meet these needs in order to provide quality health care. Distributing printed materials is one important way of providing up-to-date medical information to MS patients in a clinical care setting.

In a poster presentation at the recent CMSC annual meeting in San Diego, Sharon Peters, RN, BN stressed that while developing effective educational tools is a “challenging and lengthy process, printed teaching materials are valuable resources for MS patients and health care workers.” To ensure that the materials developed are current, accurate, and readable, it is necessary to have a regular review of these materials by patients and staff, she added.

With this goal in mind, in 2002, Ms. Peters and colleagues at the University of Calgary MS Clinic, which serves more than 3,500 MS patients, identified a need to review existing patient materials for content and quality. Specifically, they sought to determine which pamphlets should be revised and to identify topics for which new materials should be developed. Ms. Peters shared the clinic’s experience with other health care workers at the conference.

The first step in the process was to identify new topics that required educational materials as well as materials already in existence that warranted revisions. This was determined through discussions with the clinical staff and interviews with patients at the clinic.

“Educational materials currently in circulation were assessed within the MS Clinic, the Calgary Health Region (CHR), and the MS society,” she said. Through these assessments, it was determined whether each handout effectively met the needs of the clinic.

For example, after a review of existing materials, the team identified a need for the development of new educational handouts on mitoxantrone and steroids in the treatment of MS. Another goal was to revise existing educational handouts on osteoporosis, fatigue, and spasticity.

Next, an educational resources specialist provided assistance with the planning, evaluation, and printing of the new and revised materials. The CHR protocol for development and approval of the teaching materials was determined and implemented.

To develop the materials, content information was gathered through a literature search, consultation with peers, and the Canadian MS Nursing Care Plan. Special consideration was given to literacy and readability issues as well as to the legibility of the printing and whether patients would be likely to find the materials useful.

Draft pamphlets were prepared and circulated to clinic staff, physical therapists, the rehabilitation team, and the CHR Educational Specialist for review. The materials were revised based on feedback received from all sources and were then resubmitted to the review team for further evaluation. This process was repeated until all outstanding issues were satisfactorily addressed. Ms. Peters emphasized that evaluation of these materials should be ongoing.

Examples of comments from patients included statements such as, “I would like to see more information on other things to treat spasticity besides medications” and “I wish I had this information before I started taking this drug,” stated Ms. Peters. She noted that patients would also indicate on the pamphlets any information that they didn’t understand.

Staff feedback included questions on whether patients would understand medical terminology (such as the abbreviation IV), questions on the available formulations of certain medications, and comments on the writing style of the educational materials.

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—Krista Binetti

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