



Multiple Sclerosis Nursing in 2003: A Global Perspective

MS Nursing Research: Focus on Outcomes

The use of outcome measures has helped nurses articulate their special value to the well-being of patients. However, many measures currently used to evaluate outcomes do not identify or acknowledge the unique contribution of nurses, especially when it comes to treating a chronic, progressive disease such as MS, according to Diane Lowden, MSc(A), MSCN during her presentation at the last CMSC conference in San Diego.

Why Study Outcomes?

Ms. Lowden, a Clinical Nurse Specialist in the Multiple Sclerosis Program at the Montreal Neurological Hospital of the McGill University Health Centre, provided three important reasons why MS nurses should focus on nursing outcomes research.

First, one of the unique qualifications of MS specialist nurses is their accountability for the care provided, which includes quality of care, patient satisfaction, efficient use of resources, and clinical behavior.¹ Nursing-specific outcomes should be measured to ensure that MS nurses are setting and reaching the highest possible standards of accountability.

Secondly, MS nurses must demonstrate their value in the health care system because their worth may be largely overlooked by traditional outcome methods. "There remains a gap in outcomes studies in nursing because the focus is typically on costs and lengths of stay and not on equally important measures such as symptom resolution and reduction, adherence, well-being, and patient and family knowledge and satisfaction with care," she pointed out.

Finally, "there is a need for 'hard' evidence that we make a difference," said Ms. Lowden. According to a 1998 article in *Advanced Practice Nursing Quarterly*, there has been a scarcity of published evidence that nursing research has been used to influence public health policy. The study's author, Ann B. Hamric, remarked that research is a powerful tool that nurses can and should use to make a difference in regulatory legislation.² Although this is slowly changing, nursing outcomes research could have significant implications for policies relating to MS patient care, added Ms. Lowden.

MS-Specific Outcomes

Ms. Lowden discussed some of the ideas presented by the Working Group on Outcomes during the 2002 Advanced Practice Nurse Advisory Meeting in Niagara-on-the-Lake, Canada. The group developed a comprehensive model that identified

eight outcomes and described each outcome's specific relation to MS:

- **Adherence**—includes treatment, rehabilitation, and follow-up;
- **Cost**—takes into account direct and indirect costs such as length of office or hospital visit, equipment, medications, lost work days, etc;
- **Symptom resolution and reduction**—specifically includes spasticity, fatigue, bladder symptoms, and pain, as well as mood and mobility issues;
- **Complication prevention**—the primary focus is on prevention of urinary tract infections, pressure ulcers, and pneumonia;
- **Well-being**—involves patient's mood and ability to cope, sense of hope, and stress reduction;
- **Satisfaction with care by patient and family**—includes patient satisfaction with access to care; availability, comprehensiveness, and delivery of care; and the perception of being well cared for;
- **Continuity of care and care management**—factors include reduced number of emergency room, office, or clinic visits and fewer long-term care admissions;
- **Patient and family knowledge**—signifies that patients and family have an idea of what to expect in terms of treatment, symptoms, and disease course, as well as knowledge about medications, resources, care plan, etc.

The working group on outcomes also provided suggestions for interventions and ways of measuring each outcome (see sidebar).

Alligators, Swamps, and MS

The many difficulties involved in treating MS can present significant roadblocks to nursing research, said Ms. Lowden. She paraphrased an old adage to illustrate her point: “When you are up to your neck in alligators, it is difficult to think about draining the swamp.” She likened the alligators to the day-to-day workload, unpredictable crises, patients’ unrelenting symptoms, and innumerable phone calls dealt with routinely by MS nurses. “The swamp is the big picture of MS—the emotional, physical, and social consequences of the disease and the patient and family issues that arise during the coping process,” she said.

This hectic, emotionally trying environment leaves the MS nurse with “no time to think,” said Ms. Lowden. In addition, there is no reimbursement for outcomes research, limited access to libraries and computers for most nurses, and a lack of necessary databases to capture care. The support of colleagues and a supportive management environment are the exceptions rather than the rule, she added.

Finding the Bridge Over the Alligators

One important way MS nurses can overcome these obstacles is by actively disseminating information, suggested Ms. Lowden. This can be done by publishing articles in medical journals, presenting at conferences, educating oneself and others, becoming politically involved, and promoting advocacy. She also advised collaborating with other MS colleagues, offering nursing student research grants, and seeking out mentors as ways of obtaining research assistance. In addition, finding members of hospital staff or university faculty to help with research questions, design, and statistical analysis may prove beneficial, as can the assistance of academic nurses who have research training as well as access to resources. Ms. Lowden concluded her talk by encouraging MS nurses to take advantage of funding sources such as the International Organization of Multiple Sclerosis Nurses. **MSX**

—Rosalee L. Blumer

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WAYS OF MEASURING MS-SPECIFIC OUTCOMES

Developed by the Working Group on Outcomes, 2002 Advanced Practice Nurse Advisory Meeting

Adherence. Chart review, patient and family report, drug renewal sheets, consultation sheets for rehabilitation services and physical and occupational therapy, follow-up on appointments kept.

Cost. Departmental tracking mechanisms, chart reviews of interventions, managed care resource utilization, costs to patients and families.

Symptom resolution and reduction. A variety of instruments which include:

- Fatigue Impact Scale—measures the impact of MS fatigue on various aspects of the patient’s life;
- SF-36—a multidimensional instrument that is part of the Medical Outcomes survey. It measures 36 items including social functioning and bodily pain;
- MS Quality of Life Scale—a multidimensional, patient-reported, MS-specific instrument that includes the SF-36 plus items on health distress, sexual function, and overall quality life and others.

Prevention of complications. Chart review, patient’s report, emergency room visits.

Well-being. Self-reports and questionnaires, particularly:

- Jaloweic Coping Scale—reflects the ability to cope, the degree of self-reliance or reliance on others, and coping strategies used;
- Mishel Uncertainty Scale—a self-administered questionnaire that assesses the inability to determine meaning of illness-related events;
- Beck Depression Scale—a 21-item self-report used in several illnesses to measure the severity of depression;

Patient and family satisfaction with care. Questionnaire that addresses areas of satisfaction and dissatisfaction with care.

Continuity of care and care management. Hospital admission and emergency room visit rates, patient reports of support systems and resources, referrals.

Patient and family knowledge. Pretests and posttests, determination of perceived knowledge, assessment of how well self-care skills are being performed, review of logs documenting patient and family calls and reasons for calls.

Source: Adapted from Lowden D. Measuring outcomes. *Advance Practice Nursing in Multiple Sclerosis: Advanced Skills, Advanced Responsibilities*. Bioscience Communications. 2003:23-26.

CMSC Rehab Therapists Group Forms

As recently as 20 years ago, people with MS were advised to avoid physical activity because it was thought that exercise could increase symptoms or might enhance disease activity. Over the past several years, however, research has begun to dispel these myths by showing that exercise and rehabilitation can improve function and quality of life for MS patients. These relatively new findings, together with an increasingly interdisciplinary approach to MS treatment, have set the stage for the emerging role of the rehabilitation therapist in MS patient care.

“There are unique challenges for rehabilitation therapists treating people with MS,” says Brian Hutchinson, PT, President of the Heuga Center in Edwards, Colorado, which provides innovative medical and wellness programs for families affected by chronic diseases such as MS. Mr. Hutchinson is also one of the founders of the new International Organization of Multiple Sclerosis Rehabilitation Therapists (IOMSRT), which became a special interest group of the CMSC in 2002.

“We officially formed a year ago, but the organization has been about three years in the making,” says Mr. Hutchinson. “The idea came about as a result of the rehabilitation roundtable discussion at a CMSC

“We saw the success of the IOMSN and felt that it was important for rehabilitation therapists to try to become more cohesive and to share ideas with one another.”

conference a few years ago. We saw the success of the IOMSN and felt that it was important for rehabilitation therapists to try to become more cohesive and to share ideas with one another, as well as to disseminate information to other health care professionals.

“Rehabilitation is a necessary aspect of MS treatment,” he adds. “I’m hoping that our organization can bring to the forefront an additional understanding of how this is important, as well as continue the momentum of research on rehabilitation and MS that began in

the late 1990s. Our organization can serve as an advocate for research as well as for professional and patient education.”

With 50 members currently, most from the United States and Canada, the IOMSRT is still in its infancy. Mr. Hutchinson says the organization is trying to increase its membership and international scope through meetings at the annual CMSC conferences as well as other MS-related events. “We’re using a grapevine method of getting word out,” he explains, “because we don’t have a lot of funding for mass mailings and other promotional activities.”

Primary membership in the IOMSRT is geared toward physical and occupational therapists and speech-language pathologists with an interest in MS, but associate (nonvoting) memberships are available for interested parties from other occupational fields. For further information, e-mail Mr. Hutchinson at bhutchinson@heuga.org. **MSX**

Coordinating MS Research in the US

The MS care community in the United States lacks a coordinated means of developing clinical trials, recruiting patients, and maintaining a persistent, qualified network of investigators. These deficiencies have slowed progress in the discovery of new MS treatment and care strategies.

To address these needs, MS health care professionals formed the Multiple Sclerosis Cooperative Studies Group (MSCSG). Operating under the direction of the CMSC, the group’s mission is “to identify and conduct high-quality research that will further the understanding of MS disease and its effects, reduce disease activity, and advance MS therapeutics—all to improve the quality of life of MS patients.” The MSCSG’s broad objectives include developing a cooperative infrastructure for MS research, increasing MS patients accessibility to clinical trials, and facilitating the transfer of research findings to MS providers in order to have an impact on clinical practice.

To view the 2003 MSCSG prospectus or to download a registration form, go to www.ms-care.org. **MSX**

Botulinum Toxin Injections for Neurogenic Bladder Dysfunction

There seems to be no end to the medical uses of botulinum toxin (Botox®), and one application that is gaining interest in the field of MS care is for treatment of bladder dysfunction caused by detrusor-sphincter dyssynergia (DSD).

At the CMSC conference earlier this year, researchers from the Mellen Center for MS Treatment and Research at the Cleveland Clinic reported the results of their trial, which used botulinum toxin injections to treat documented DSD in 12 MS patients.¹

The patients (10 female; mean age 51.2) had three sessions of 100-IU botulinum toxin injections into the external sphincter, spaced four-weeks apart. Improvement over baseline was determined on the basis of post-voiding residual volume (PVR); patients' voiding diaries recording frequency, urgency, leakage, and retention; patients' perception of the severity of urinary symptoms; and quality of life measures based on two standard urological questionnaires.

After the treatment period, there was significant improvement in PVR, patient-reported urinary frequency, and perception of urinary symptoms, but quality of life scores and the other parameters did not change significantly. The authors, led by Francois A. Bethoux, MD, concluded that botulinum toxin injections appear to relieve some of the symptoms of DSD, but that further study of this treatment modality is needed.¹

Positive results in MS patients also have been reported at other centers. Nine MS patients with DSD received external sphincter injections of botulinum toxin (100 IU) in a study performed at the University of Pittsburgh.² At baseline, all had urinary retention, hesitancy, urgency, and infection history, and four required intermittent catheterization. After the injections, all were able to void spontaneously. The authors reported that patients experienced no acute complications, such as general paralysis or respiratory depression, and that no patients developed stress incontinence during the follow-up period.

A larger study from Taiwan published recently by Kuo³ enrolled 103 patients with urinary dysfunction from a variety of causes, in-

cluding 29 with DSD. Botulinum toxin doses ranged from 50 to 100 IU. This author reported a success rate of 84.5%; 39% of patients reported excellent results and 46% had significant improvement. Among patients for whom treatment was successful, mean maximum voiding pressure, maximal urethral closing pressure, and post-void residual pressure had improved significantly at evaluations two to four weeks after treatment. Interestingly, 39 out of 45 patients were able to have their indwelling catheters removed or intermittent catheterization discontinued.

Botulinum toxin was first applied to the treatment of bladder conditions in 1998. Published literature reviews on this modality note that the best indication seems to be DSD caused by either MS or incomplete spinal cord injury.⁴ The effects of the injections last between two and nine months, depending upon the dose and the number of injections given.^{3,4}

An obvious downside is the high cost of the botulinum toxin (about \$400 for 100 units) if the patient's insurance does not cover the procedure. **MSX**

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