Multiple Sclerosis Nursing in 2004: A Global Perspective

Fostering Hope in MS Patients

Multiple sclerosis (MS) is commonly diagnosed between the ages of 20 and 40—typically the most productive years of a person's life. Receiving a diagnosis of MS presents a threat to independence and may cast doubt on a person's ability to make meaningful contributions to family and society. In addition, the unpredictable nature of the disease causes many people with MS to feel ill-equipped to plan for the future. "It should come as no surprise, then, that depression, helplessness, and hopelessness commonly occur in patients with MS," said Linda Morgante, RN, MSN, CRRN, MSCN, who spoke about the importance of hope in MS patients' lives at the 2004 CMSC conference in Toronto.

"It is important for MS nurses to understand the elements of hope and to recognize when patients are struggling with feelings of hopelessness," said Ms. Morgante. "The nurse is the pivotal player in ensuring that the individual with MS maintains a sense of hope throughout the illness. In addition to providing education, counseling and referrals, the nurse can help the MS patient focus on feelings and ideas, recognize personal reasons for living, and establish both short-term and long-term goals."

Hope and Health

Hopelessness has been defined as lacking the energy for either imagining or wishing, said Ms. Morgante. "It involves a desire to give up, to be unable to imagine beyond the limits of present circumstances, and the loss of the ability to dream."

On the other hand, "hope is an essential element of human life; it embodies our vision of the future, our opinion of ourselves and others, and our sense of control over the events and directions of our lives," she explained.

Hope has been shown to play an important role in health and coping during chronic illness. "Hope may help a patient with MS to continue functioning more successfully and to remain independent for a longer period of time," stated Ms. Morgante. "Hope may not only bolster a patient's self-esteem and sense of well-being but also may have a synergistic effect on more conventional medical therapies." A study of breast cancer patients found that feelings of helplessness/hopelessness had a moderate but detrimental effect on five-year event-free survival.[1] In a study of relapsing-remitting MS patients on glatiramer acetate (Copaxone®) therapy, Fraser and colleagues found that hope helps to promote adherence to therapy.[2]

How Can the MS Nurse Inspire Hope?

Several characteristics contribute to a patient's level of hopefulness, Ms. Morgante noted. Self-esteem, feelings of competence, and control of one's life are related to hope. "An underpinning of faith, whether expressed as conventional religious faith or simply as a feeling of being connected with a higher being, has also been found to have a positive impact on a patient's hopefulness."

Several nursing measures can help encourage hope, stated Ms. Morgante (Table 1). Before intervention can occur, however, the nurse must recognize the degree of hope that a patient has, she explained. As a frequent caregiver, the nurse can identify and evaluate behaviors that reflect hope (Table 2).

In addition, MS nurses can ensure that adequate resources are available to support hope. This may involve ensuring access to the workplace. A study by Foote et al[3] showed that employment correlated positively with higher levels of self-esteem and hope in MS patients. In addition, minor modifications such as grab bars and a chair in the shower can make bathing easier and safer for the patient and increase a sense of independence, Ms. Morgante advised.

"Creating hope that extends forward into time gives most patients a

Table 1. Nursing Measures That Encourage Hope

- Establish realistic expectations
- Help to maximize abilities
- Educate, counsel, refer, advocate
- Use humor
- Provide distraction
- Reframe the experience
- Help to savor the moment
- Encourage socialization
- Teach relaxation modalities such as:
  —yoga and meditation
  —deep breathing
  —Tai chi
  —massage

sense of a future, which severely depressed patients may lack," said Ms. Morgante. However, hoping in the moment or "taking it one day at a time" may be appropriate for MS patients whose fears and anxieties are focused on the future uncertainties surrounding the illness. One study[4] found that hope shifts as individuals move through an experience for long periods of time. "Hopes and dreams of recovering at some point in the future undergo a transition to focusing on one day at a time," said Ms. Morgante. "The experience is reframed to a comfortable place in the present, which promotes a sense of control and renews hope."

Many MS patients express fear of becoming burdens to their family and friends, Ms. Morgante noted. "The nurse can help the patient explore these feelings and pinpoint key relationships that are vital to hope. Maintaining and strengthening these relationships are crucial to a patient's emotional well-being." The nurse also may help to facilitate communication between the patient and friends and/or family.

Table 2. Patient Behaviors That Reflect Hope

- Verbalizes future goals
- Shows motivation to reach goals
- Imagines a brighter tomorrow
- Reminisces about past successes
- Sees options for self
- Maintains a sense of control
- Anticipates positive outcomes
- Relates to family, friends, or caregivers in supportive and reciprocal ways
- Feels connected to a higher being; spirituality

Social isolation caused by bladder and bowel problems may occur during the course of MS. "The nurse can provide practical solutions for managing problems that may interfere with social activities," suggested Ms. Morgante. "For example, self-catheterization techniques can be taught, drugs may be prescribed to assist with urinary urgency and incontinence, and bowel habits can be regularized with a high-fiber diet and supplements, giving the patient greater comfort and self-confidence in social situations.

"Most importantly, nurses inspire hope when they feel hopeful themselves," concluded Ms. Morgante. Research shows that patients rely on the hopeful attitudes of the health care provider.[5] **MSX**

—Rosalee L. Blumer

References

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Managing Spasticity in MS: A Nurse's Point of View

Approximately one third of MS patients modify or eliminate daily activities as a result of spasticity.[1] "Many life functions can be affected by spasticity. It affects patients' ability to work, think, and learn, which affects self-image and confidence," said Danuta Gogol, RN, MA, LPC, during a workshop on the topic at the 2004 CMSC conference in Toronto.

"If someone experiences a great deal of spasticity, it takes a lot of energy for the person to move around and perform daily tasks," explained Ms. Gogol, a clinical nurse specialist at the Mellen Center for MS at the Cleveland Clinic in Ohio. Spasticity causes fatigue and may also cause difficulties with concentration. In addition, it can have an impact on the entire family and tends to limit

Table 1. Factors That Complicate Spasticity

- Fatigue, imbalance, lack of coordination, weakness
- Infection, injury, inflammation, constipation, other illnesses, general state of health
- Medications (selective serotonin reuptake inhibitors, beta interferons)
- Environment (heat, cold, humidity)

how people interact socially.

Spasticity is complicated by several factors, noted Ms. Gogol (Table 1). "The condition can involve the entire body, which includes the upper and lower limbs, neck, back, abdomen, and pelvis." Patients who experience spasticity primarily in their legs may also experience spasticity in other parts of the body, she noted.

Nonpharmacologic Treatments

Complementary and alternative methods of care can be used along with any pharmacologic measure to treat spasticity, according to Ms. Gogol. Martial arts like tai chi sometimes help to reduce spasticity by relaxing the muscles, she said, as do other activities such as energy work, touch, massage, relaxation, and visualization. "We have patients who use acupuncture in combination with pharmacologic treatments, which many find helpful," she remarked. Heat, cold, and water therapies are also used by some patients. Although there is little clinical evidence for alternative modalities, anecdotal evidence points to their usefulness, she said. "It's important to keep in mind that these exercises may also worsen spasticity in some cases. Patients seem to know what works best for them and that's what they should be doing."

Table 2: Antispasticity Medications

First-line therapies
- baclofen (Lioresal®)
- tizanidine (Zanaflex®)

Adjuvant therapies
- diazepam (Valium®)
- clonazepam (Klonopin®)
- dantrolene (Dantrium®)
- clonidine (Catapres®)
- muscle relaxants

Physical and occupational therapy should be incorporated into a patient's treatment program when there is any degree of spasticity, said Ms. Gogol. Techniques for energy conservation and optimization have been shown to improve fatigue and other quality of life measures.[2] Gait training, orthotics, bracing, and electrical stimulation are also beneficial. "MS nurses should work closely with physical and/or occupational therapists and patients to get spasticity under control. This may reduce the amount of medication patients need to take," she added.

Pharmacologic Modalities

There are a number of treatment choices available for spasticity (see Table 2). The first line of therapy is usually oral baclofen (Lioresal®). Because baclofen may cause muscle weakness and sleepiness, it should be started slowly and given in titrated doses, noted Ms. Gogol. This is also true of most other medications that are used to treat spasticity. Anticonvulsants or antidepressants may be useful, she noted. Narcotics are sometimes used but do not appear to be as effective. Nonsteroidal anti-inflammatory drugs can help to reduce pain as well as spasticity, she added.

"Patients tend to request steroids frequently because many feel it improves spasticity," Ms. Gogol pointed out. However, it is probably best to cut down on the use of steroids for spasticity because of the potential for adverse effects. "It's a good idea to minimize the use of steroids for treating spasticity because MS patients may need to take them to treat exacerbations," she advised.

For more severe cases of spasticity, baclofen is sometimes administered using a surgically implanted pump. The Multiple Sclerosis Council for Clinical Practice Guidelines recommend intrathecal baclofen as an effective treatment for patients with severe disability (an EDSS score of 7 or greater).[3] **MSX**

—Rosalee L. Blumer

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Developing an MS School for Patients

Many newly diagnosed MS patients do not have a clear understanding of the disease or what the diagnosis means for them. Although one-on-one sessions provide an important opportunity for the clinician to educate patients about MS, there are several limitations to this approach. First, doctors, nurses, and other health care providers may be severely limited in the amount of time they have to spend with each patient. In addition, a patient who has just received a diagnosis of MS and is still reeling from the shock of the "MS label" may be unable to process the information during an office visit, let alone think of questions to ask a clinician.

Table 1. Topics Reviewed at MS School for Patients

- Symptoms and signs of MS
- The definition of MS
- Pathophysiology of MS
- How a diagnosis is made
- Disease classification
- Disease prognosis

In order to address the problems inherent in the "tired doctor/overwhelmed patient" scenario and improve patient education about the disease, Alexander D. Rae-Grant, MD, and Nancy Eckert, RN of the MS Center of the Lehigh Valley Hospital in Pennsylvania developed an "MS School for Patients." They discussed the philosophy behind the school during a presentation at the last CMSC meeting in Toronto.

Table 2. MS School Structure

- Small groups (20 participants maximum)
- Intimate environment
- Non-threatening atmosphere
- Patient participation encouraged
- Complimentary lunch for attendees

"First of all, MS is a lifelong disorder, and those receiving new diagnoses are in need of a good—and consistent—introduction to the disease," said Dr. Rae-Grant, who is Director of the MS Center and Chief of Neurology at Lehigh Valley Hospital. "For instance, many words associated with MS need defining for this patient population, such as *attacks*, *exacerbations*, *lesions*, *demyelination*, *axon*, *myelin*, and *atrophy*, among others," he said.

"One of the main goals of the course is to define the important educational elements for newly diagnosed patients," explained Ms. Eckert, who is Clinical Director of the Lehigh Valley Hospital MS Center. Several key subject areas are addressed in the program (Table 1).

During each session, patients are encouraged to ask questions in order to enhance social interaction and help them to gain a sense of comfort with the faculty and other patients. They are also encouraged to pick up information and pamphlets provided by the MS center that explain the disease and its treatment.

"During the program, we avoid selling anything, patronizing, trying to control information, and 'doctor speak,'" Dr. Rae-Grant stressed. This type of interaction benefits both the patients and the medical team because patients feel comfortable bringing new ideas to the center, he said. For instance, patients who attended the MS school came up with several new fund-raising ideas for the center.

Learning groups are kept small, said Dr. Rae-Grant, because large groups impede direct communication and many patients find them to be intimidating. Groups of 20 participants or less offer a non-threatening, intimate environment, added Ms. Eckert (Table 2). "All newly diagnosed patients are encouraged to attend." She noted that the MS school is open to neurology patients not affiliated with the MS center. **MSX**

—Rosalee L. Blumer