OBJECTIVES
After reading this article, nurses new to the care of people with MS will be able to:
◆ Assess select psychosocial factors in MS
◆ Identify mutually established goals for a plan of care
◆ Implement nursing strategies to address select psychosocial factors in MS

INTRODUCTION
Because multiple sclerosis is a variable and unpredictable disease, the diagnosis is upsetting for most people, and can create physical, emotional, social, and spiritual consequences. MS affects young people at a time when life is filled with anticipation and endless possibilities. Nursing care in MS is a multi-dimensional process with a primary focus on caring. Nurses address the multifaceted problems associated with the disease to help patients and families to cope with the lifelong impact of MS.

This module will address some of the major psychosocial issues that emerge for patients with MS and their families, and affect how they cope with the disease. The interplay among these psychosocial variables, and their relationship to disease uncertainty and symptomatic variability, will also be discussed.

BACKGROUND
MS is a disease with an unpredictable course and a neurologic presentation that is unique for each individual. People with MS experience an array of neurological symptoms that fluctuate on a day-to-day basis and that are often worsened by elevations in body temperature and fatigue. Disease modifying therapies have provided hope for people with MS by altering the natural history of the disease. Five agents, interferon beta 1-a (Avonex®), interferon beta 1-b (Betaseron®), interferon beta 1-a (Rebif®), glatiramer acetate (Copaxone®), and mitoxantrone (Novantrone®) have been clinically proven to reduce frequency and severity of flare-ups of the illness and to probably slow the progression of disability. New and improved symptomatic therapies, used alone or in combination, can reduce fatigue, pain, spasticity, and changes to bladder, bowel, and sexual function. But the disease remains incurable, and depression,
helplessness, and hopelessness are common among the MS population (Fischer & Crawford, 1994). Nurses are presented with a challenge when assessing the psychosocial impact of the disease on the person with MS and others in their lives. In some ways, it is easier for the patient and nurse to deal with the physical manifestations of MS than to address the psychosocial issues. Helping the patient to cope with psychosocial issues requires a high level of empathy and unconditional regard from the nurse.

ASSESSMENT

The nursing process frames nursing practice, and is useful when caring for the psychosocial concerns of the person with MS. The major areas of the assessment include: mood; self-esteem, self-efficacy, and self-care; relationships; lifestyle changes; and hope.

Mood

When assessing how a person is responding emotionally, the nurse can fairly quickly and easily attend to mood by observing a person’s body language, tone of voice, and expressions of optimism versus pessimism. Fear, anger, anxiety, and depression are associated with a general perception of loss of self-control (Kerns, 2000), and are common manifestations of the illness particularly when the disease is new, flaring up, or transitioning to a progressive course. How people are dressed and groomed, their ability to make eye contact, their posture in a chair, the spring in their step, their facial expressions, and the content of their conversation can help a nurse determine mood at any particular time. Assessing patterns of sleeping, eating, sexual functioning, and adhering to therapeutic regimens also provide clues to a person’s emotional state.

Self-esteem, self-efficacy, and self-care

Self-esteem, self-efficacy, and self-care are important concepts that, independently and in combination, help predict a person’s ability to cope with an illness. Self-esteem is an aspect of self-concept that reflects how adequate and worthwhile a person feels. Self-efficacy means that a person believes he/she is competent and capable of accomplishing a task. Self-efficacy has been shown to predict adherence to therapeutic regimens in a variety of chronic illnesses. A study of patients taking glatiramer acetate (Copaxone) (Fraser et al, 2001) showed a statistically significantly higher level of self-efficacy among people who maintained regular injection schedules over a one-year period. Because confidence and competence can predict how well people will take care of themselves, inquiring about dietary habits, use of dietary supplements and complementary therapies, exercise regimens, and methods of coping with stress are important areas for nursing assessment.

Relationships

Social support is an important aspect of coping with chronic illness. Social support has been well documented in the literature as a predictor of coping, and includes provisions for attachment and intimacy, feeling connected to others who share similar experiences, communicating
and networking with others, and having access to family, friends, and health care providers who can care for emotional and physical needs (Weinert, 1989).

The nurse can assess this realm by noting who accompanies the person to the doctor’s visits, asking the person to identify key players who are perceived to be supportive, and exploring how the person accesses the help of these individuals when in crisis.

**Lifestyle changes**

Assessing a person’s role in the family, workplace, and among friends helps to establish a baseline by which to measure future changes in role. People who are accustomed to a leadership role and perceive themselves as being in control have more difficulty coping when MS affects their physical and cognitive selves. Losing mobility can not only bring about a loss of independence, but also can force people out of the workplace and prevent previously enjoyed leisure activities, causing social isolation. Simply asking the person, “how do you see yourself at the workplace,” or “what is your role in your family,” can uncover valuable information and help establish a sense of how a person will cope with role changes in the future. Other areas that can be included in the lifestyle assessment include means of transportation; disclosure of MS to family, friends, and co-workers; hobbies and pastimes; and financial concerns, including insurance.

**Hope**

Hope helps people with MS to continue to live more successfully with their disease. Hopeful feelings improve a person’s self-esteem and well being, and may have a synergistic effect on conventional therapies. Nurses can assess behaviors that reflect hope in the people they care for. Hopeful people are able to verbalize their goals, are motivated to achieve their goals, expect to accomplish their goals, and are able to make alternative plans if their goals are not achieved. They can imagine that if they feel bothered by symptoms of MS one day, the next day holds the possibility that the symptoms will improve. People who can remember how they coped successfully with difficult situations in the past, can recognize all of their options, feel in control, and are not overwhelmed by any given situation, are generally more hopeful individuals. Supportive and reciprocal relationships, feeling connected to a Higher Being, using humor, and relaxing with modalities like meditation and yoga are all signs of a more optimistic person (Morgante, 2000).

**GOALS**

Nursing care to ease the psychosocial burdens associated with MS include improving mood, bolstering self-esteem and self-efficacy, promoting self-care, facilitating relationships, preserving lifestyle, and inspiring hope. Achieving the goals of each of these interconnected concepts requires creativity, ingenuity, and alterations to the nursing care plan as the patient’s condition changes.
INTERVENTIONS

Education, counseling, advocacy, and referrals are nursing measures used everyday in practice to achieve the goals mutually established with patients and families. Nursing education and counseling are important interventions that help to alleviate fears and anxieties in people with MS. The nurse is a knowledgeable resource for clarifying information about the disease and its manifestations. Offering support, reassurance, and follow-up in person and via the telephone help people with MS connect with the nurse. This connection creates a lifeline for patients dealing with the challenges of living with MS.

Education

Teaching patients how to care for themselves, how to manage symptoms, how to cope with stress, and how to maintain optimal health and wellness is a primary nursing intervention. The education process often includes family and friends which helps support relationships. Teaching patients to deal with symptoms such as fatigue, urinary urgency and incontinence, constipation, and pain is a life enhancing measure that helps to improve a patient’s mood by empowering self-care.

Finding the time to teach patients is an ongoing nursing challenge in a health care environment that does not support extended time for office visits. Planning a brief education session at each visit helps the nurse to maximize time and energy. Handouts, booklets, and teaching in group settings are some ways to cope with the limits imposed by the health care system.

Counseling

Depression is more common in MS than in any other chronic illness. It is estimated that up to 60% of the people with MS will experience one major depressive episode during the illness (Schiffer et al, 2001). Anger and hostility are manifestations of depression, and can often be diffused by using a calm tone of voice and a gentle touch. Counseling patients to deep-breathe, learn ways to relax, and nurture the spiritual self are nursing interventions that improve mood and inspire hope. Pharmacologic interventions may also help to alleviate depression. The newer class of selective serotonin re-uptake inhibitors (SSRIs) are frequently tried as an initial intervention to relieve symptoms of depression. There are anecdotal reports that the use of SSRIs will also reduce fatigue in a select group of people with MS (Krupp, 2002), particularly if their fatigue is secondary to their depression.

Involving family and friends in the plan of care is an essential element of the counseling process. People often focus their hopes on others. The desire to remain emotionally strong, to live longer, and to remain as healthy as possible for the welfare of others is a valuable healing force that can be nurtured by the nurse whenever possible.

If looking ahead becomes too painful, or creates unnecessary fear and anxiety in a person who faces uncertainty because of the nature of MS, the nurse can help reframe the experience to look at what is hopeful in the moment. A song, a photograph, a poem, a flower, a hug, a kiss, a
snowflake, a candle, a fragrance, the sun, stars, or the moon shining brightly are just a few of life’s simple pleasures that bring joy, and are easy to access.

Advocacy

Nurses are at the forefront of advocating with third-party payers, employers, and the community for better access to care and for quality of life for people with MS. Nursing measures that support the advocacy role include ensuring that the workplace remains barrier free, encouraging alternative transportation modalities, writing letters for parking permits, providing medical justification for diagnostic testing and medications, promoting life planning and use of legal directives (including advance directives), and exploring disability rights and eligibility (Northrup, 2002).

Referrals

Maintaining solid relationships with good referral sources is an important nursing intervention. Referrals not only fortify the caring process, but also help people maximize abilities. Common referrals for people with MS include physical, occupational, and speech therapy; the local chapter of the National Multiple Sclerosis Society for services such as peer support; and medical consultations such as urology, gastroenterology, psychiatry, and ophthalmology. Other referrals may include nutritional support, home care, pain specialists, equipment and supply vendors, and social services agencies.

CONCLUSION

Various psychosocial issues emerge for people living with a chronic disease like MS. The intimacy of the nurse-patient relationship provides an opportunity to identify and treat psychosocial issues before they become problematic. For this article, mood; self-esteem, self-efficacy, and self-care; relationships; lifestyle changes; and hope were selected because of their relevance to nursing practice. The nursing process was utilized as a framework to help nurses assess, plan, and develop strategies to treat these particular psychosocial realms.

REFERENCES


**REVIEW EXERCISE**

1. Depression is a symptom which  
   a. Occurs only when MS progresses  
   b. Can manifest as anxiety, anger, or hostility  
   c. Cannot be managed with standard interactions  
   d. Worsens the autoimmune pathology

2. A hopeful person  
   a. Avoids eye contact  
   b. Blames others for his/her shortcomings  
   c. Can envision possibilities  
   d. Is easily overwhelmed

3. Nursing interventions to ease psychosocial distress include  
   a. Education, counseling, advocacy, and referrals  
   b. Prescribing antidepressants  
   c. Discontinuing interferon therapy  
   d. Calling a social worker to take over the case

4. Self-efficacy means  
   a. Feeling adequate and worthwhile  
   b. Independently caring for oneself  
   c. Using alternative therapies  
   d. Feeling competent and capable of accomplishing a task
5. To help patients preserve their lifestyle, the nurse can
   a. Recommend filing for social security disability
   b. Advocate for alternative modes of transportation to the workplace
   c. Recommend an exercise regimen
   d. Delay referral to rehabilitative services

Answers: 1 b; 2 c; 3 a; 4 d; 5 b