The Evolution of Nursing Care in Multiple Sclerosis

J Halper, MSN, ANP, FAAN
Executive Director
Gimbel MS Center
Executive Director
Consortium of MS Centers
Teaneck, NJ

Abstract

Multiple sclerosis (MS) is a chronic, frequently debilitating neurologic disease that affects young adults in the prime of their lives. Until recently, treatment focused on symptom management rather than on disease modification. Patients' contacts with the health care system were limited to the diagnostic period, episodes of acute attacks, and periods of disease progression.

With the advent of disease-modifying agents, the focus of care in MS has changed from one of maintenance and crisis intervention to a more positive and proactive approach. The nurse working in the field of MS has emerged as an important member of the health care team, playing a vital role in the ongoing care of and interaction with patients and their families. Nursing care in MS is a collaborative effort whose goal is self-awareness and self-responsibility; its activities involve supporting a great deal of self-care by patients, families, and care partners.

The nurse working with MS patients is a care provider, facilitator, advocate, educator, counselor, and innovator. The challenges of the disease require many creative interventions in a wide variety of settings. The list of care needs is long and complex. Interventions range from instruction in the use of medications, both oral and injectable, to bowel and bladder management strategies, to the improvement of mobility. The dynamic nature of the disease, along with its psychosocial, economic, and physical implications, calls for ongoing skill development and up-to-date information on the part of the nurse interested in MS care.

Introduction

Multiple sclerosis (MS) is a chronic disease of the central nervous system that affects young adults in the prime of their lives. It is diagnosed almost twice as frequently in women as in men. Most patients initially experience a relapsing-remitting course in which exacerbations are followed by periods of remission. Often, the disease converts to a progressive course, in which chronic problems gradually accumulate and acute relapses no longer occur. Common symptoms of MS include fatigue, cognitive changes, emotional problems (particularly depression), altered mobility, visual abnormalities, bladder and bowel dysfunction, and sensory problems.

A Brief Overview of MS

An international survey was conducted in 1996 to standardize the terminology used to describe the clinical course of the disease. This led to 4 major classifications of the disease: (1)
relapsing-remitting; (2) primary progressive; (3) secondary progressive; and (4) progressive-
relapsing. Relapsing-remitting MS is characterized by clearly defined relapses followed by
periods of lack of disease progression. Primary progressive disease is demonstrated by a nearly
continuous worsening disease course that may be interrupted by occasional plateaus and
temporary minor improvements. Secondary progressive MS is defined as an initial relapsing-
remitting disease followed by progression with or without occasional relapses, minor
remissions, and plateaus. Finally, progressive-relapsing MS is progressive disease from the
onset with clear acute relapses, with or without recovery.3

The cause of MS is not known, although it is suspected to be the result of an autoimmune
response to a viral infection in a genetically susceptible individual. Several viruses have been
detected in patients with MS, but no single virus has been identified as a causative agent. It is
possible that more than one virus is capable of triggering this response.1

Nursing Assessment and Promoting Wellness

Assessment

The nurse has emerged a key member of a team of health care professionals tending to
patients with MS and their families. Nurses see patients in the acute care setting, long-term
programs, rehabilitation units, outpatient MS centers or clinics, neurologists offices, or in the
home. Day-to-day contact, knowledge, and awareness of critical issues in MS make the nurse
well-positioned to perform patient assessments. In addition, the nurse often serves as a liaison
between the patient, family, and health care providers and can be instrumental in the design,
implementation, and coordination of a comprehensive treatment plan for the patient.2

The first type of evaluation commonly made by the nurse is an assessment of the physiologic,
emotional, social, and environmental needs of the patient. For example, a nurse is perhaps the
best person to observe subtle changes in the patient’s bowel and bladder function, mobility,
swallowing, vision, and skin integrity. Keen observation makes it possible to treat such
symptoms promptly, thereby preventing the development of serious complications.

Because patients with MS are at increased risk for depression and suicide,1 it is also important
for the nurse to pay close attention to the psychological state and needs of the patient.
Changes in behavior, expressions of helplessness, hopelessness, anger, or sadness, and suicidal
statements should be noted and reported to other members of the health care team. A study of
suicide among patients with MS found that those who had committed suicide were more likely
to have been male, unemployed, experiencing financial stress, more severely disabled, in a
progressive phase of the disease, experiencing unendurable psychic pain, withdrawn, and
isolated from a support network.4

A nurse who is aware of signs of cognitive dysfunction in the patient (poor concentration,
confusion, short-term memory problems, difficulty following directions)5 should alert the
physician, who may suggest a formal cognitive evaluation. In addition, the nurse can enlighten
the patient, family, and friends that this symptom is a part of MS rather than a sign of
stubbornness, inattentiveness, or irritability. Social, vocational, and recreational needs are
assessed by the nurse as well.

Nurses are able to assess the relationship between the patient and his or her care partners, and
they can often determine whether the care partners are helping or hindering the patient. The
educational level of the family (how much they understand about the disease process,
symptoms, and treatments) can also be evaluated. It should be made clear to everyone
involved that two thirds of patients with MS do not become severely disabled and that most
people with MS live a relatively normal life. Any gaps in the patient’s knowledge can be filled in
with readings, support groups, or individual educational sessions with the nurse.6 Finally, it is
important for the nurse to evaluate the patient’s motivation as well as that of the care partners. Success in the management of MS depends on the attitude and outlook of the patient and his or her support network.

**Promoting Wellness**

Although pharmaceutical remedies are generally the focus of disease management discussions, they are not the only way to manage MS. The proper combination of rest and physical activity is an integral part of good health and wellness, and it is an area in which nursing can strongly influence the patient’s experience of the disease.

By scheduling activities during periods in which energy levels are high and by taking regular rest periods, patients can effectively conserve their strength. Exercise is essential to maintaining muscle strength and tone and joint mobility. Swimming is an ideal activity because cool water prevents elevation in body temperature and buoyancy facilitates movement. Other highly recommended physical activities are stretching exercises, yoga, and tai chi. Heat and humidity can intensify MS symptoms; therefore, it is recommended that the patient’s living and working environments be kept as cool as possible, preferably with air conditioning. Should a patient have a fever, it is important to reduce body temperature and to treat the underlying cause as promptly as possible.

A good diet can promote wellness, while inadequate nutrition can make a patient more prone to infection. Maintenance of proper body weight and a balanced intake of nutrients can promote a healthier state. Adequate fluids, fruits, vegetables, and fiber can prevent constipation, a common complaint in MS. Cranberry juice and prune juice can increase urinary acidity and act as bacteriostatic agents; orange and grapefruit juice have the opposite effect and should be limited in their intake. Many patients experiment with dietary modifications to manage their MS. Nurses are in an excellent position to promote nutritional wellness, taking into consideration the patient’s opinions, cultural and economic constraints, and physical impairments.

**Disease-Modifying Treatments**

**Disease Modification and Nursing Care**

During the past 7 years, three agents—the ABC drugs—have become treatment options for reduction of exacerbations and modification of the disease course. These include the interferons—IFN-b-1b (Betaseron®), IFN-b-1a (Avonex®), and glatiramer acetate (Copaxone®). Interferons are immunomodulating agents that are injected subcutaneously every other day (Betaseron) and intramuscularly once a week (Avonex).

Glatiramer acetate, which mimics myelin basic protein competing for binding sites and may interrupt the inflammatory cascade in the demyelinating process, is a daily subcutaneous injection. Side effects of the interferons include a flulike reaction, spasticity, site reactions in IFN-b-1a, and altered hematologic profile. These can be minimized by timing the administration of drug in the evening, medicating with nonsteroidal anti-inflammatory drugs (NSAIDs), rotating injection sites, and using sterile technique. Copaxone does not cause flu-like symptoms, but has been reported to occasionally cause a mild, transient systemic reaction that resolves spontaneously over a short period of time. Education, emotional support, and skills development will assist the patient and family to successfully manage these complex procedures. Nursing care in patients who are assuming responsibility for self-injection includes education about the medication, management of side effects and how to minimize them, injection techniques, and reasonable expectations about the therapy. The nurse’s role may also include assisting the patient to obtain insurance approval for these medications. Occasionally, patients will not have adequate coverage for treatment and may require assistance to access support programs that have been developed by the pharmaceutical industry.
Acute Exacerbations and Nursing Care

Acute exacerbations are usually treated with oral or intravenous corticosteroids, which have been shown to shorten the duration of the attacks. Steroids have no long-term benefit on the disease course. Intravenous therapy is usually methylprednisolone, 1 to 3 g daily for 3 to 5 days. This may or may not be followed by an oral taper or dexamethasone or prednisone. Some physicians treat patients with a course of oral corticosteroids only. Long-term administration of corticosteroids is not recommended because of the significant toxic effect of these drugs. Side effects of long-term steroid use include susceptibility to opportunistic infections, hypertension, cataracts, muscle wasting, osteoporosis, and diabetes. Nurses play a role in the acute management of MS by educating patients about the proposed therapy, overseeing adherence to the prescribed regimen, monitoring patients for side effects, and encouraging patients during this difficult period.

Symptom Management in MS

Primary symptoms in MS are those that are the direct result of demyelination in the central nervous system. Symptoms most commonly experienced include weakness, fatigue, tremor, pain, bladder and bowel dysfunction, paralysis, spasticity, visual changes, and diminished sexual function, including impotence in men.

Secondary symptoms are complications that are caused by the underlying impairment in MS. These include falls, injury, reduced activities of daily living, lack of sleep, urinary tract infections (URIs), incontinence of bowel and bladder, skin breakdown, contractures, problems with the environment, and diminished opportunities for intimacy.

Tertiary symptoms are psychosocial or vocational problems, occurring as a result of primary and secondary symptoms in MS, that are not treated and become an overwhelming part of the patient’s life. These include loss of job; shift in roles; divorce; loss of financial, social, vocational, and environmental mobility; the stigma of disability; and reactive depression. The nurse and the MS team should take measures to alleviate primary symptoms, thereby dramatically reducing the incidence of secondary and tertiary symptoms. It is important to note, however, that the greatest impact on the patient’s quality of life is taking measures to reduce social isolation and promoting participation and productivity despite the persistence of primary symptoms.

Fatigue

Fatigue is a common symptom in MS that does not correlate well to the patient’s physical status. Typically, a patient will become tired after exercise or as the day progresses. Some may also complain of sudden episodes of fatigue. Regular rest periods or short naps, performing moderate exercises, and using assistive devices such as motorized scooters are effective energy-conserving techniques. Medications for fatigue include amantadine, pemoline, and fluoxetine (amantadine, 100 mg bid; pemoline, 18.75 mg bid; fluoxetine, 20 mg qd, and modafinil, 100 mg or 200 mg). It has been found that depression can be a cause of fatigue, and treatments such as counseling and a supportive social environment can be therapeutic in combating this problem.

Spasticity

Spasticity is caused by involuntary muscle contractions and is characterized by stiffness. This symptom can also result in pain and limitation of motion. Sudden stretching of muscles, changes in position, and use of tight clothing or equipment may trigger and worsen spasticity. Treatment consists of slow stretching programs, appropriate physical activity such as swimming, mechanical aids, medications such as baclofen, tizanidine, clonazepam, and dantrolene sodium. These medications may have sedative effects, and patients must be instructed about the potential side effects as well as dosage and administration. A baclofen
pump, in which medication is delivered continuously through intrathecal infusion, is the next step should these interventions prove ineffective. Surgical techniques such as nerve blocks and cutting of the tendons are infrequently used for intractable spasticity.8

**Bladder and Bowel Dysfunction**

Many patients with MS experience some type of bladder problem during the course of the disease. Symptoms may include urinary urgency, frequency, incontinence, nocturia, and frequent UTIs. Bladder dysfunction is managed by obtaining a careful history, ruling out a UTI through a urine analysis and culture and sensitivity test, and obtaining a post-void residual volume (PVR) of urine. This will help diagnose whether the patient has a failure-to-store bladder, a failure-to-empty bladder, or a bladder that combines the 2 problems. Treatment of the failure-to-store bladder (one that has a PVR volume of less than 100 ml) consists of anticholinergic agents such as oxybutynin, hyoscyamine sulfate, and propantheline bromide, avoidance of diuretic foods such as caffeine and aspartame, and maintaining a regular schedule for bladder emptying. Tolterodine, a muscarinic antagonist, may also be effective in a bladder that fails to store substantial amounts of urine.15 The failure-to-empty bladder is treated with intermittent catheterization by either the patient or a care partner, or with indwelling catheters. Combined dysfunction encompasses both the failure to store and the failure to empty. Treatment usually consists of anticholinergic agents along with a catheterization program, either self-care by the patient or family, or indwelling.16

Bowel dysfunction can manifest itself as either constipation or diarrhea. With constipation, an adequate intake of fluids and fiber, a bowel program that consists of regular and adequate time for evacuation, and stool softeners usually are effective in the management of this problem. Oral and rectal stimulants can also be used occasionally under nursing supervision, but frequent use of enemas and harsh laxatives should be avoided. Diarrhea is usually a secondary effect of overuse of laxatives or stool softeners or may occur with severe constipation when there is leakage of intestinal contents around stool impaction. Diarrhea may be treated with remedies that reduce gastrointestinal motility and fluid loss. Bulk-forming supplements may be of benefit.16

**Sensory Symptoms**

Sensory symptoms such as pain, numbness, burning, and tingling may be a great source of concern to the patient.8 Avoidance of noxious stimuli, investigation for underlying infections, and neurologic evaluation for exacerbations are recommended for these symptoms, especially if they occur acutely.8

Pain in patients with MS may be either a primary symptom or the result of the disability associated with the disease. Tension or migraine headache may be a primary symptom and is usually treated with prescription nonsteroidal anti-inflammatory agents or with the over-the-counter pain relievers. Retro-orbital pain may be due to optic neuritis, an exacerbation of MS. Treatment is with steroid therapy, usually given intravenously over 3 to 5 days. Trigeminal neuralgia or tic douloureux is a sharp facial pain associated with MS. Symptomatic relief can be achieved by treatment with gabapentin, phenytoin, amitriptyline, or carbamazepine.8 Intratable neuralgia can be treated with a surgical procedure called percutaneous rhizotomy, in which the sensory root fibers of the trigeminal nerve are severed. Dysesthetic pain, or a burning or electric shock sensation in the extremities or trunk, can be alleviated with the same medications used for trigeminal neuralgia or with topical application of capsaic acid cream. Secondary pain is usually musculoskeletal in nature and is the consequence of poor posture or balance. Patients who ambulate with inappropriate assistive devices, sit with poor posture, or fall frequently are subject to this symptom. Treatment consists of moist, moderate heat, massage, physical therapy, pain relievers, anti-inflammatory agents, and correction of the underlying problem.8
Cognitive Implications of MS
Cognitive dysfunction is common in patients with MS. It is estimated that up to 65% of those with the disease experience some degree of cognitive loss—some so mild that it does not affect their lives. Others have such a great degree of loss that they are no longer able to function independently. Temporary lapses in cognitive function may also occur during exacerbations. Cognitive disorders in MS often consist of retrieval deficits, difficulty with concept formation, problems with abstract reasoning, behavioral fluency, and planning and organizational skills. A nurse who suspects signs of cognitive dysfunction in a patient should consult other members of the health care team so that specific deficits can be diagnosed and interventions offered. A full battery of neuropsychologic examinations often reveals where the deficits lie so that compensatory strategies can be developed.

At the present time there is no pharmacological treatment for cognitive dysfunction in MS, although some medications and rehabilitation activities are being investigated. Nevertheless, identification of cognitive dysfunction can lead to referrals for services. Documentation of a severe cognitive disorder may qualify patients for disability benefits. Frequently, behaviors in the patient that are caused by diminished cognition—stubbornness, crankiness, mood swings, and inattentiveness—must be interpreted to family members and coworkers. Education, along with individual and family counseling, can help the patient and care partner cope with this problem.

The Nurse’s Continuing Role
Planning for the Patient’s Future
Nurses who care for patients with MS should be aware of specific concerns that the patients have about their disease, such as: What will happen to me and my family? Can I continue working? How disabled will I become? Often, preexisting insecurities in the patient become exaggerated. Nurses must assist these patients to become educated about their disease and suggested treatments. Patients should be encouraged to seek counseling to overcome depression and possibly to affiliate with support groups for an ongoing supportive social environment.

Because MS usually strikes during the productive years of life, issues related to employment can be a prominent concern. It is estimated that 25% of patients with MS are working and that another 25% desire to return to the workforce. Fatigue and other symptoms experienced during relapses and in progressive disease and the unpredictability of future disease course in MS can impose major obstacles to employment. Nurses, social workers, and physicians can be supportive in encouraging a patient to continue to work, if possible. Working and productivity are important to a person’s quality of life. Finding a job that does not require physically demanding work, staggering work hours, taking naps, and working from home are strategies used to assist patients to remain in the workforce. Those who are no longer able to work should be encouraged to find volunteer activities appropriate to their physical and mental function. Adaptive devices such as scooters, voice-activated computers, and visual aids can assist patients in these activities.

The Nurse as an Educator
The nurse has a vital role in the education of patients and their family members. It is very important to encourage patients, who may be overwhelmed by their new diagnosis, to move out of a passive role and to assume a proactive stance about MS. The educated patient is more likely to feel a sense of empowerment, acceptance, and well-being. The nurse can assist in this process by referring patients to literature, newsletters, and short-term orientation groups, and by explaining the disease process, symptoms, tests, and technical terms. It is important for the nurse to help establish reasonable expectations for proposed treatments, to educate patients in self-care and wellness, and to prepare the patient for side effects. A nurse’s support, advice,
education, and expertise as part of a therapeutic partnership can do much to advance MS from an overwhelming disease to a set of solvable problems in the lives of patients and their families.

**Family Issues in MS**
The patient and her partner must consider all aspects of parenting before deciding whether or not to start a family. Pregnancy has been shown to have a protective effect on MS, while the postpartum period results in a higher risk of relapses. It is very likely that many couples would welcome information about this choice. A nurse should encourage couples to be realistic about the problems associated with MS; to evaluate their emotional, financial, and family support; to assess their flexibility with parenting roles; and to think beyond the initial stages of infancy. Couples should also be made aware of the resources available to them, including educational materials, family therapists, and support groups.

A parent's diagnosis of MS can be difficult for a young child. A child's sense of security can be threatened by the disability of the parent. In addition, a child may have to shift roles and assume increased responsibility in the home. While a parent with MS should avoid giving elaborate details of symptoms and disability, children become more anxious when they sense that the truth is being kept from them. Parents should give age-appropriate answers to questions and seek supportive material from sources of information such as the National Multiple Sclerosis Society and the MS Society of Canada. Family counseling can allow family members the opportunity to air their concerns and develop strategies for coping.

**Nursing Care in Advanced MS**
The severely disabled patient with MS has a need for intensive nursing care. Patients with dysphagia must be given dietary modifications to prevent aspiration and nutritional deficits. Thick fluids, soft foods, and special feeding techniques must be initiated and taught to care partners and providers. In patients who are no longer able to swallow safely, feeding must be done through a feeding tube, which is inserted into the stomach.

Skin care is another concern for the severely disabled. Pressure sores often occur over bony prominences such as on the sacrum, ankles, and elbows, and on pressure points such as on the heel. Measures to prevent pressure sores include the use of wheelchair cushions, wheelchairs that are well fitted to the patient, assistive devices (side rails, trapezes, etc) to promote repositioning, and good skin care to promote skin integrity.

With advanced MS patients, the nurse is challenged to provide the patients and families with a realistic hope and a message of caring. This is particularly difficult today in light of the new disease-modifying medications, which are offered to patients with MS but which are not appropriate for the severely disabled individual. Nursing care may consist of rehabilitation strategies, such as a program of stretching; linking patients to supportive services and networks; and intermittent appropriate psychosocial interventions as indicated by the needs of the patient and family.

**Conclusion**
The nurse working with patients with MS has many roles: care provider, facilitator, advocate, educator, counselor, and innovator. Additionally, the nurse often serves as a liaison between the patient, family, and health care providers and can be instrumental in the design, implementation, and coordination of a comprehensive treatment plan for the patient. A nurse's support, advice, education, and expertise as part of a therapeutic partnership can do much to advance MS from an overwhelming disease to a set of solvable problems in the lives of patients and their families.
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