

Nursing Grand Rounds: Multiple Sclerosis

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Abstract: Multiple sclerosis (MS) is a highly variable, unpredictable disease and one of the most life-altering diagnoses a person can receive. Because it usually strikes in the prime of life, frequently progresses to disability, and has no cure, MS can make a strong emotional impact—not only on those who suffer from it, but also the healthcare team. Because MS is such a complex, multifaceted disorder, nurses who care for people with MS are faced with numerous clinical challenges. Many of the challenges are unique to MS, demanding, and time-consuming. Well-informed nurses are positioned to evaluate and explain the disease process, assist in the alleviation of symptoms, educate partners and families, and help improve quality of life. A case example can help nurses understand the real-life concerns of a person with MS.

Multiple sclerosis (MS) is a chronic neuroimmunologic disease of the central nervous system (CNS) that affects the brain, spinal cord, and optic nerves. It is characterized by the occurrence of random patches of inflammation that result in the loss of myelin—the insulating substance that surrounds nerve fibers in the white matter of the CNS. Loss of myelin, however, is no longer the only hallmark of the disease. In recent years, it has been discovered that axons become irreversibly damaged as a consequence of the immune system's attacks on myelin early in the disease. This axonal loss may be a major cause of the persistent neurological deficits in MS. Early treatment with disease-modifying agents is especially recommended in light of this evidence (National Multiple Sclerosis Society, 2003).

Three injectable immunomodulating agents—interferon beta-1a (Avonex, Rebif) and glatiramer acetate (Copaxone)—have emerged as encouraging treatment advances for relapsing MS since interferon beta-1b (Betaseron) was first approved for relapsing MS by the Food and Drug Administration (FDA) in 1993. These agents reduce the number of relapses by up to 30%, reduce the severity of attacks, and possibly delay the onset of disability. In November 2004, the FDA approved a new drug for use in MS. Natalizumab (Tysabri) is a

monoclonal antibody administered intravenously. Another drug approved by the FDA for use against MS is mitoxantrone (Novantrone). This chemotherapeutic agent is administered to those whose relapsing MS is worsening, as characterized by more frequent or severe relapses, limited recovery after relapses, or a steady decline with relapses (i.e., secondary progressive MS).

Most people with MS suffer episodic acute symptomatic attacks, also known as exacerbations or relapses. These episodes last from one day to several days or weeks and represent new disease activity. Temporary worsening of symptoms due to elevated body temperature from infections and viral illnesses are called “pseudo-exacerbations” and remit as the fever is reduced and the underlying cause dissipates. But when severe worsening of existing symptoms or emergence of new symptoms are not associated with fever or infection, such attacks usually are considered to be exacerbations and are treated with intravenous (IV) methylprednisolone. The most common treatment course is 1,000 mg over 2 hours daily for 4–6 days (van den Noort, 1999), though the schedule may vary. High-dose IV steroids usually are tapered and may be followed by a course of oral steroids. Short courses of IV steroids are usually well tolerated and safe.

These agents, along with innovations in symptom management, have improved the quality of life (QOL) for people with MS. They also have intensified the challenges of treatment management for nurses providing care. Because the effects of MS are so variable, each case is unique and presents its own set of symptoms and challenges. A case report illustrates the diverse problems faced by nurses and other members of the healthcare team and demonstrates how effective management strategies can significantly improve outcomes for patients with MS.

Maria's Story

Maria* is a 30-year-old, single, Hispanic female who lives with her parents and sister in an apartment. She was diagnosed with MS at the age of 19 years and currently has secondary-progressive MS (Table 1) with many disabling symptoms. Maria is heavily dependent upon her family, home nursing staff, a personal assistant, and rehabilitation therapists. Because of the consistent and professional care she receives from her family and healthcare providers, Maria feels her QOL is as good as it can be, given the severity of her condition.

*Not her real name

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Table 1. Classifications of MS (Lublin & Reingold, 1996)

Relapsing-Remitting MS: Persons with relapsing-remitting MS experience clearly defined relapses, or episodes of acute worsening of neurologic function, followed by periods without disease progression. Usually, recovery is complete after each relapse, although there may be residual effects. Over time, relapsing-remitting MS often evolves into a more progressive course.

Primary-Progressive MS: People with primary-progressive MS experience a slow, continuous worsening of function that is not interrupted by distinct relapses.

Secondary-Progressive MS: People with secondary-progressive MS experience a relapsing-remitting disease course at onset, followed by progression with or without occasional relapses, minor remissions, and plateaus.

Progressive-Relapsing MS: People with progressive-relapsing MS experience progressive disease from the onset, with clear, acute relapses. Unlike relapsing-remitting MS, the periods between relapses are characterized by continuing disease progression.

Maria experienced her first symptoms in 1987, when she was a college student. She sought medical attention for diplopia (i.e., double vision) and was referred to a neurologist, but because the double-vision disappeared shortly after receiving the referral, she did not pursue the matter. Four months later, her diplopia returned, and Maria consulted a neurologist. Other symptoms were revealed during her evaluation, including “heavy legs” and Maria’s inability to run up and down stairs. A magnetic resonance imaging (MRI) scan and the results of a lumbar puncture that revealed elevated protein and oligoclonal bands confirmed the neurologist’s suspicion that Maria suffered from MS.

Now, a decade after her diagnosis, Maria has a number of disabling symptoms that challenge her and her healthcare team. These include the following:

- bladder and bowel dysfunction
- visual impairment
- impaired mobility caused by spasticity and paralysis of her lower extremities
- severe fatigue
- tremor
- pain

Bladder Dysfunction

Bladder dysfunction affects as many as a 90% of all MS patients (Anderson & Bradley, 1976; Blaivas et al., 1979; Goldstein, Siroky, Sax, & Krane, 1982; Schoenberg & Gutrich, 1980) and recurrent urinary tract infections (UTIs) are common. There are different types of bladder dysfunction that may occur. Therefore, it is important to emphasize the need for regular nursing assessment of bladder function in MS. Bladder symptoms have a significant impact on QOL and, if untreated, may lead to serious complications.

Maria is typical in this regard; she experiences about one UTI a year and sees a urologist twice a year. Three years ago, she developed a serious acute UTI with high fever, urgency, frequency, and incontinence. She was hospitalized on the neurology unit and required a course of IV antibiotics to treat the infection. Due to incomplete bladder emptying, she was intermittently catheterized until her discharge from the hospital.

Although Maria can void on her own, she has a bladder dysfunction known as “failure to empty,” which has several different underlying pathologies. In Maria’s case, the bladder attempts to empty (i.e., the detrusor muscle contracts); however, the external sphincter also contracts, creating detrusor-sphincter dyssynergia, or uncoordination. Symptoms such as urgency, hesitancy, double voiding, increased frequency, a feeling of incomplete emptying, and postvoid residual urine of more than 100 mL are suggestive of failure-to-empty syndrome. The retained urine creates a medium for bacterial proliferation and subsequent UTIs, as well as development of calculi from mineral precipitates.

Maria requires intermittent catheterization to eliminate the postvoid residual urine. Prior to her hospitalization, she was referred by her urologist to a nursing agency to learn self-catheterization. Difficulty with motor coordination, loss of sensation in her fingertips, and bilateral tremor, however, have made it impossible for Maria to accomplish this task herself; and today, Maria undergoes intermittent catheterization twice daily by visiting nurses. She also takes oxybutynin chloride extended-release tablets, (Ditropan XL), which relax the bladder (i.e., detrusor muscle) and relieve urgency and incontinence.

Another form of bladder dysfunction, called “failure to store,” is even more common in people with MS. Symptoms of urgency, frequency, incontinence, nocturia, and a postvoid residual urine of less than 60 to 100 mL are suggestive of failure to store. This form of bladder dysfunction is treated with anticholinergic agents, behavior modification, and avoidance of diuretics and bladder irritants, such as caffeine.

Although Maria was unable to perform self-catheterization, her condition was managed successfully with nursing intervention. Complications that once were considered an unavoidable part of MS can be prevented through appropriate strategies.

Bowel Dysfunction

Some degree of bowel dysfunction also is reported by about 33% to 60% of people with MS (Chia et al., 1995; Fowler & Henry, 1999; Hinds et al., 1990; Nordenbo et al., 1996). Constipation is particularly common, but involuntary bowel movements also may occur and can be particularly distressing to the patient (Holland, 1999). In addition to experiencing ordinary causes of constipation,

people with MS may have “slow bowel” as a direct result of impaired neurological function in the sacral area of the spinal cord. Medications used to treat other MS symptoms, such as anticholinergics, also can cause constipation. Weakened abdominal muscles, general weakness, and immobility also may contribute to constipation.

Nurses evaluated Maria’s constipation, identified several contributing factors, and developed a management plan that included adequate fluid and fiber intake (1.5–2 liters per day and 15 g dietary fiber; Namey, 2002). They also used a bulk-forming agent and mini-enemas, when needed. Because Maria requires a wheelchair for mobility, physical inactivity contributes to her constipation. Nurses helped her compensate for this inactivity and her weakened abdominal muscles by teaching her the Valsalva maneuver. This maneuver comprises a deep inhalation followed by a forceful contraction of the abdominal muscles in conjunction with a strong, forceful expiration.

When fecal incontinence is the problem, much of the management is similar to that for constipation. Anticholinergic drugs can be helpful when a hyperactive bowel is the underlying cause of the incontinence, but these drugs can affect bladder function and should be carefully monitored.

Visual Impairment

Maria’s initial symptom of diplopia was what prompted her to seek medical attention. Visual symptoms are common in MS and affect up to 80% of patients at some point during the course of their disease (Frohman, 1999). Diplopia results from an eye movement abnormality known as internuclear ophthalmoplegia. Maria has continued to experience recurrent bouts of double vision, which have improved without treatment. In some instances when double vision occurs suddenly as an acute episode, it may be treated with steroids (Schapiro, 2003).

Impaired Mobility: Spasticity

MS frequently results in impaired movement largely because of spasticity, difficulties with balance and coordination, tremor, and weakness. Every symptom that affects mobility has the potential to affect QOL and needs to be included in the assessment and management plan.

Maria suffers from severe spasticity. Spasticity is an increase in muscle tone caused by involuntary contractions of opposing muscle groups characterized by stiffness and spasms. Spasticity occurs most frequently in the muscles that are responsible for maintaining upright posture. A small amount of spasticity may not have a significant effect on function, but when it becomes more prominent, it can hamper gait, seating, and comfort.

Treatment may begin with a rehabilitative physical therapy program. Exercises or mechanical aids, or both,

in combination with oral medications, especially baclofen (formerly Lioresal) and tizanidine (Zanaflex), represent part of this program. Baclofen and tizanidine doses must be carefully determined for each individual, because too little will be ineffective, but too much produces fatigue and a feeling of weakness. In the majority of patients, oral baclofen or tizanidine, or both, are successful at relieving spasticity, including sensations of tightness and pain.

Unfortunately for Maria, oral baclofen ceased being effective as her spasticity worsened. In the case of such intractable spasticity, the implantation of a baclofen pump for continuous drug delivery often is the next step, as it was in Maria’s case. The baclofen pump, which is implanted in the abdomen with a catheter tunneled to the spinal canal, delivers the baclofen directly into the intrathecal space surrounding the spinal cord. The rate of drug delivery can be adjusted to meet individual need (Frankel, 2001). Because the required doses of baclofen are so low, side effects also are low and there is less associated fatigue than with much higher oral dosages. This technique may be especially useful for nonambulatory patients such as Maria, as well as for ambulatory MS patients who have difficulty with high doses of oral antispasticity medications.

Impaired Mobility: Lower Extremity Paralysis

Paralysis of Maria’s lower extremities was a major impairment that could not be reversed. The detrimental effects were addressed by rehabilitation, which teaches adaptive skills, such as transferring to and from a wheelchair, and prescribes assistive equipment and aids, such as personalized wheelchairs, wheeled walkers with seatrests, and ankle-knee orthoses for “foot drop.” Maria has maximized personal-mobility independence and safety through the use of an electric wheelchair tailored to her personal needs and abilities. Rehabilitative physical and occupational therapies have helped Maria prevent complications (e.g., contractures and decubiti), learn skills for maximum independence, and enhance QOL.

Fatigue

Studies report that as many as 75% of people with MS experience fatigue, and 50%–60% report that fatigue is one of their most disabling problems (Fisk, Pontefract, Ritvo, Archibald, & Murray 1994; Freal, Kraft, & Coryell, 1984; Murray, 1985). There are many causes of MS-related fatigue: excessive energy needs (e.g., walking up stairs), deconditioning, depression, and medication side effects. But much of the fatigue associated with MS is idiopathic and is described as a generalized, rapidly induced tiredness that “comes out of nowhere.” Fatigue can exacerbate other symptoms, including cognitive dysfunction.

Maria manages her fatigue and maintains energy for a variety of activities through personalized strategies for conserving energy taught to her by visiting nurses and occupational therapists. Nurses recommended that Maria sleep regular hours and avoid unnecessarily late nights, plan ahead, make a weekly schedule of activities, recognize her limits, pace her activities, and take short rest periods during prolonged activity. Maria has found that 15-minute rest periods several times a day are quite restorative and may substitute for more prolonged rest.

Several medications can be prescribed to relieve fatigue; however, their efficacy has not been well documented. Amantadine, an antiviral agent, is effective in some patients. The newest agent is modafinil (Provigil), which is approved by the FDA for narcolepsy. A daily 200 mg dose of modafinil has proven beneficial for Maria.

Tremor

Tremor was a major challenge for Maria. Tremor is one of the most frustrating symptoms to treat in MS and can be a major cause of diminished function. The most common tremor in MS occurs as a result of demyelination in the cerebellum and its pathways, which often results in a gross tremor that occurs with purposeful movement of the arm or leg.

Initially, tremor affected Maria's nondominant left hand. Several years later, her right hand became affected, making activities of daily living, especially feeding herself, very difficult. A number of medications have antitremor effects but tend to be very sedating. Maria has been greatly aided by nonpharmaceutical approaches, in particular, physical and occupational therapy. Techniques that involve light weights, pulleys, and isometrics are used to teach the person with MS to compensate for tremor by providing as much stability for the limbs as possible. Maria is now able to pick up a glass and to feed herself with minimal spillage.

Pain

Two-thirds of MS patients experience pain at some time during course of their disease (Maloni, 2000). Pain in MS occurs both as a consequence of the disease and as a consequence of the disability it produces. This pain—acute, subacute, or chronic—can be severe and may have multiple causes. The following are common pain syndromes related to MS:

- **Neuralgia:** the paroxysmal pain that occurs along the distribution of a peripheral nerve; common forms among MS patients include trigeminal neuralgia and glossopharyngeal neuralgia
- **Tonic spasms:** brief, unilateral muscle twitching, cramping, and spasms, usually of the limbs, preceded and accompanied by intense radiating pain, burning, or tingling

- **Optic neuritis:** episodic or constant eye pain associated with inflammation of the optic nerve
- **Dyesthetic extremity pain:** usually a burning, “nagging” pain
- **Complex regional pain syndrome:** neuropathic pain that is shooting, stabbing, burning.

Pain is a symptom that demands serious attention, because it has a pervasive impact on mood, capacity to work and rest, and relationships. Healthcare providers also should realize that not all pain can be ascribed to MS, and they should look for additional causes, as well.

Maria occasionally suffers from trigeminal neuralgia, which is managed by carbamazepine (Tegretol). This and other antiepileptic drugs are used to manage most MS-related pain. Surgical denervation is an alternative in extreme cases. Complementary therapies (e.g., acupuncture, massage, moist heat, meditation, guided imagery, biofeedback, tai chi, and so forth) are useful to many MS patients and should be considered in the treatment plan (Halper, 2002; Pignotti & Holland, 1998).

Psychosocial and Vocational Needs

Although many people with MS can continue to work and be independent, Maria, unfortunately, cannot. The severity of her MS has left Maria quite dependent upon others. However, she is committed to remaining socially connected and productive in spite of her disability.

Quite understandably, there is a high incidence of depression, helplessness, and hopelessness in the MS population. One study has found the suicide rate among MS patients to be 7.5 times higher than for the general population (Sadovnick, Eisen, Ebers, & Paty, 1991). Clinical depression in MS should be taken seriously and treated aggressively.

The impact of this disease on self-esteem, marital and family relationships, friendships, community involvement, and social activities is all-encompassing. Even when the individual's psychological state is positive, the energy required to maintain a social network despite increasing disability can be daunting. Counseling, support groups, and rehabilitative services can prevent social isolation and enhance QOL.

Maria's opportunities for social interaction and productivity largely center upon her volunteer efforts. Accessible urban transportation allows Maria to volunteer once a week at the National Multiple Sclerosis Society, where she reviews educational materials. The time spent at the society gives Maria a chance to interact with peers, stay abreast of the latest developments in MS, and feel that she is helping others.

“For me, the opportunity to come to the society and volunteer has been a blessing,” Maria says. “If it weren't for this, I would be home feeling very depressed.”

Summary

MS is a complex and unpredictable disease that presents unique challenges to healthcare professionals. Nurses can enhance the care of MS patients by obtaining an awareness of the complexities of the disease and the many successful management strategies. Nurses in a variety of settings will encounter individuals with MS, and sensitivity to the significant impact of the disease on health and QOL is critical.

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