



Multidisciplinary Management of a Patient With Multiple Sclerosis

Part 2. Nurses' Perspective

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Nurses are important members of the VHA, which employs more nurses than does any other system—89,000. Nursing care is patient-centered, whole person, and multidisciplinary. Nurses enhance access to care through alternative communication strategies, such as telemedicine.^{1,2} Besides clinical care, nurses focus on health promotion, disease prevention, health education, attentiveness, and counseling.²

Nurses working in the Multiple Sclerosis Centers of Excellence (MSCoEs) adopt the precepts of the Patient Aligned Care Team of the VA. Also, nurses who care for patients with multiple sclerosis (MS) establish, maintain, and sustain care that is culturally sensitive and wellness focused and incorporates family and community resources with the goal of living well with MS.³

ESTABLISHING CARE

Educating patients and their families about MS, its symptoms, and self-management skills at the time of diagnosis is paramount. That said, nurses are less concerned with MS immune pathology and white matter lesion count and are more concerned with helping patients maintain hope and optimism.⁴ Patients' abilities to adapt to chronic disease, manage symptoms and drug adverse events (AEs), and participate fully in life are essential after receiving a diagnosis of MS. Establishing care for patients with MS should be focused on relationship building, open communication, sharing information, and building trust. Developing partnerships becomes the goal, and ongoing assessment builds the case for the continuum of care.^{4,5}

WILLIAM'S STORY

As William walked into the nurse's office, careful to allow one finger to linger on the wall and backs of furniture, the nurse recognized a young man heavy with a new MS diagnosis. William was tentative, bristly, and trying to maintain his balance. The nurse noted William's too-big clothes, part army fatigues, part athletic wear. William stated he was there only because his primary care provider wanted him to get a diagnosis for his balance problems. Developing a trusting relationship was paramount in caring for William.

William boasted of his athletic prowess and strength. Indeed, William was strong with full power in all extremities. He recounted that poor balance kept him from competing successfully in an athletic event requiring that he walk across a plank over electrified water. As the nurse listened, she recognized William's reticence to accept his MS diagnosis. The nurse understood that previous history could affect his ability to accept a diagnosis and the treatment plan at this time. The nurse's role was to help William navigate the VA health care system and access its resources. William was encouraged to participate in My HealthVet (<https://www.myhealth.va.gov>) in order to exchange secure messages with the nurse. His messages revealed a lonely, angry man, distant from family and friends.

William acknowledged problems with balance and thinking. He quit a job he had held for 5 years as a financial advisor for fear that coworkers would discover he could no longer think clearly. He also quit his position as a Boy Scout leader for fear people would discover his poor balance. He stopped interacting with his family; he

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felt badgered by their probing questions about his health. William suspected that his family was gleeful he was no longer the smartest and wealthiest sibling. The nurse and William together defined and developed mutual goals, including management of his primary concerns of balance and thinking.

On William's next visit, he sported a T-shirt that read, "Fight the Bully." William explained that MS was the bully, and he would never give up the fight. The nurse suggested that the best fighting strategy was disease-modifying therapy (DMT). The nurse reinforced the information given to him about DMTs by the neurologist and reviewed the current research on treatments. The nurse offered strategies for remembering to take medication, sent secure messages, and phoned frequently to assess and encourage William and to announce availability if needed.

Continuing Care

The nurse role in the continuum of care is to assess patient self-management skills and provide, when needed, interventions to restore self-management to the highest level.⁴ Although William told the neurologist he was not having any difficulty injecting the DMT, William told the nurse he stopped the DMT. "This drug is not helping my balance, I fall all the time," he told the nurse.

William reported that his family said not to believe the doctors at the VA. "They are giving you experimental medication—be careful—don't take their drugs." Finally, William admitted that he hated injecting himself and had painful injection-site reactions. The nurse recognized an opportunity for teaching and reinforced realistic expectations of the DMT, which do not improve MS or its symptoms but may reduce the rate of relapse, slow disease progression, and limit white matter lesions seen on magnetic resonance imaging.

The nurse invited family members to come to the clinic, and William's brother and sister attended a group education event. They both had many questions about MS. William was very quiet, as it became evident that his family wanted information and to help. The family was not the hindrance to care as William previously described. The nurse helped William reframe his attitude toward the role of his family in his care.

William talked about something he learned in an MS chat room about natural therapies. The nurse provided evidence-based and reliable information, including the MSCoE website (<http://www.va.gov/ms>), containing

information for professionals as well as patients with MS.⁶

William refused to go back to an injectable DMT. The nurse therefore discussed several oral medication options; however, William wanted to "fight" MS with alternative therapies. He said that exercise, a plant-based diet, and magnet therapy were all he needed. Those choices provided the opportunity to discuss complementary and alternative medicine (CAM) and use the latest American Academy of Neurology guidelines on CAM.⁷ The nurse encouraged and validated William's desire to treat his MS with diet and exercise but focused the conversation on evidence-based therapies. He ultimately decided to initiate an oral DMT.

William had an opportunity to participate in the VA-sponsored Winter Sports clinic. His roommate at the games, John, was also a veteran with MS, and William developed a relationship with John. John was taking an oral DMT to manage his disease. William returned from the games and requested the same DMT that John used.

The nurse recognized the importance of peer-to-peer influence and helped William feel in control of his MS. He was grieving lost abilities. Continuing care meant boosting William's self-esteem, enhancing coping, allaying misconceptions and false beliefs, reframing life events, decreasing feelings of chronic sorrow, and offering hope.⁴

Sustaining Care

The goal of the nurse in sustaining MS care is focused on maintaining well-being, coordinating referrals, identifying community resources, and advocating for comprehensive care.³ Nurses continually reformulate the patient's primary and long-term goals of care. They exercise their role as advocates, helping fulfill patient needs while maintaining good stewardship of resources. Nurses sustain the therapeutic relationship over time, providing caring throughout the MS disease trajectory.

As the disease progresses, nurses are vigilant to both prevention of complications and management. In this regard, the MS Assessment Tool is a useful portal to document dynamic changes in disability and therapy and track AEs. Infection, pain due to immobility, wounds, difficulty with respiration and swallowing, and neurogenic bowel and bladder are initially assessed and managed while preserving the patient's physical, emotional, and spiritual values. Last, nurses cultivate

relationships with other providers for personalized referrals, ensuring continuity and efficiency of care.⁴

The nurse and William discussed his greatest difficulties, which were primarily social. Without a job or income, William relied on savings to pay his mortgage, car loan, utilities, and other bills. William admitted that he had very little money to buy food as his savings dwindled. The nurse connected William with both VA social workers and a veterans service organization (VSO) and brokered a relationship for William with a community organization, the local chapter of the National Multiple Sclerosis Society (NMSS).

BENEFITS AND ASSISTANCE

The NMSS was able to offer some limited financial assistance. William enrolled in a support group for newly diagnosed patients sponsored by NMSS and joined a class for people with MS and balance difficulties. The VSO helped William with his application for service connection for his disability. Multiple sclerosis is considered service connected if neurologic symptoms leading to a diagnosis are established during the military career or within 7 years of service discharge.⁶ William's first symptom occurred 5 years after his army discharge. The social worker helped William apply for Social Security Disability Insurance (SSDI). The nurse also wrote letters, and he was subsequently approved for both SSDI and VA service connection for his MS. As a result, William accessed vocational rehabilitation services through the Veterans Benefits Agency.

Consults to prosthetics and rehabilitation services are essential for optimizing patient safety and energy. The opportunities for William in the VA health care system exceeded many private sector plans in that all medically necessary durable medical equipment is available without charge. William was able to focus on managing his MS without worries about food, shelter, or health care.

The neurology outpatient clinic brings the nurse, neurologist, psychiatrist, neuropsychologist, social worker, dietitian, urology, occupational and physical therapists, wound care nurse, and prosthetics representative together in one place. Patients can access the care of each discipline during a single clinic visit. Quality of care, cost savings in travel, and patient satisfaction are clear rewards. When William encountered difficulty driving to

the VA for clinic appointments, he was referred to the Driving Program at selected sites and evaluated for assistive technology in his vehicle or an adaptive vehicle.

If driving can't be maintained, care can be sustained through clinical video telemedicine, use of VA travel services, and home care. Should his family need to provide care, respite options also are available through the VA to maintain care at home for as long as possible. If his level of disability increases and his home is not accessible, William will be eligible for a Home Improvement and Structural Alterations grant to maintain safe access and egress and an Adaptive Housing Grant for an accessible home. Should residential living be needed, this option is also provided to eligible patients.

CONCLUSION

Veterans with MS served by the MSCoE network have access to a knowledgeable clinical team. Nurses have the skills to build enduring relationships. The nurse can instill confidence, empowering patients to take control of MS self-management. Nurses have the unique ability to establish, maintain, and sustain care for the person diagnosed with MS throughout the disease trajectory. Most important, nurses in specialty care clinics realize the VA mission—to offer access to efficient, quality care. ●

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