Assessing Psychosocial Issues in MS

Nurses are dedicated to empowering individuals with multiple sclerosis (MS) to live the best life possible and to be responsible for that life. Because nurses are the health providers with whom individuals with MS have the greatest contact, they provide the most opportunities for intervention, education, and referral to help with their physical and psychosocial problems.

For the nurse, assessment of individuals with MS is an ongoing process. It begins on first contact with an individual and continues throughout their relationship, which is one that involves caring and trust but not dependency. “We try to empower people to be independent and to deal with the problems caused by their MS but also to know when and how to get help,” said Carol Saunders, RN, BSN, of the Neurology Center of Fairfax in Virginia. She spoke at the North American MS Nurse Advisory meeting held November 4, 2001 in Dallas, Tex.

Relationships

In assessing psychosocial issues, nurses first look at a person’s relationships and support system. “Is there a spouse or significant other? Can that person be present at your next meeting? Does that individual want to learn about MS and will he or she feel comfortable sharing any concerns as they come up? These are all questions that must be answered to obtain an accurate picture of an individual’s situation,” observed Ms. Saunders. If the person is not married, his or her expectations as to dating and future marriage plans should be explored.

If the person with MS has children, the nurse often can help in discussing MS with them. “Children have a sense when something is wrong; they need to know and not to feel guilty,” said Ms. Saunders. Or, in the event of a child having MS, the question might be “Do the parents feel guilty and do they hover, making their child uncomfortable or do they not accept the diagnosis and not want to address it? Older parents often are so concerned with their own problems that they do not have the coping skills necessary to help an adult child who has been given a diagnosis of MS,” she continued.
A different situation would involve a person whose child or children are left as caregivers. In such a case, there are educational programs at the center or at the local MS society that will help children of individuals with MS. In addition, the person should be asked what kind of help is needed with his or her extended family.

**Values and Career**

Another area that nurses explore is that of an individual’s values, beliefs, and goals. A person’s ethnic background shapes those values, and they often are very different. “For example, in some cultures, a wife may be expected always to provide complete care for her husband, and a role change because of MS becomes completely unacceptable to both husband and wife,” Ms. Saunders commented.

Nurses also look at a person’s career or occupation, taking into account such factors as the nature of the work environment and the response of coworkers and supervisors. “The career goals of the individual need to be identified and a determination should be made as to whether that person needs help in changing some of those goals. One reason career goals might need to be revised is that there may be cognition problems that need to be addressed,” stated Ms. Saunders.

**Coping and Self-Esteem**

In determining where to get the help and support individuals need, it is necessary to look at how the person has handled problems in the past. “Is this a young person who has never really had to confront the idea of not being ‘perfect’ before and is now insecure because of the uncertainty and unpredictability of his or her future? Does that person need counseling to be able to make decisions about the future that are neither overly pessimistic nor overly optimistic? Again, these questions need to be answered,” stated Ms. Saunders.

Another component that affects coping strategies concerns the communication patterns of the person and his or her family. Such patterns may lean toward silence or discussion, sharing or holding back. With respect to children, there may be open exchanges or protection.

The level of an individual’s sense of self-esteem is also important. Ms. Saunders stressed that someone who has been able to adjust to change in the past and to make substitutions when he or she was unable to do certain tasks will fare much better. “It is easier for someone who is older rather than for the younger person to adjust to change and look back at past successes on which to build. If the person feels defeated, he or she will need some counseling in order to cope,” she said.
An individual also will be helped by a strong sense of hope, and a strong spiritual or religious belief. “In our society today, it is difficult for us to accept that the future is unknown. We are taught always to plan for the future,” Ms. Saunders continued. The goal is for someone to be able to go from “I’ll never use a wheelchair” to “I’ll do whatever I need to do to remain as independent as possible.” We instill hope in people who have MS using medicines, symptom management, and our own positive attitude,” she commented.

Ability to Educate and Stress Reaction

According to Ms. Saunders, another critical step in the psychosocial assessment is determining the degree to which a person with MS is open to learning. Is this an individual who is cognitively able to assimilate information about MS and to put things into perspective, or someone in a state of denial who does not want to learn about MS? “Denial can be a good way of coping in that it permits the individual to go on living without relating everything in his or her life to MS; however, denial can be harmful if it keeps a person from coming for any necessary treatment,” Ms. Saunders explained. She also pointed out that while some people may never quite “accept” their disease, they must learn to tolerate and handle it.

The way in which a person responds to the stress of having MS is also crucial. “The main distinction is between someone who is unable to deal with the stress of having an exacerbation and someone who is able to accept such an event as a setback and then move on,” said Ms. Saunders. Variations on these distinctions include the person who analyzes every feeling, calls for help, and yet cannot cope with the presence of any symptom as well as the person who is outwardly “the picture of control and support” until an exacerbation of symptoms occurs.

The Continuum

Nursing assessment of psychosocial issues takes place on a continuum. “Life is change, and as the physical status of someone with MS changes, that person’s coping strategies change as well and must be continually reevaluated,” Ms. Saunders stated. MS nurses, with their ability to assess, teach, support, and care, are genuinely able to help individuals make needed adjustments. However, according to Ms. Saunders, one of the most important skills nurses need to have is the knowledge of when to make a referral to a physical therapist, a social worker, a psychologist, a psychiatrist, or a family therapist. “If we work in an MS center, we know where to find these specialists and how to make the referral. However, many MS nurses are in MS centers that are part of private neurology practices. These nurses must take on the added burden of having to be aware of all the resources available in their communities and must know which insurance company allows those covered to go to which resource; this is a very difficult task,” she said.

In concluding, Ms. Saunders summed up the nurse’s place in assessing psychosocial issues. “The role of the nurse is unique in that it focuses on a person’s complete well-being and how MS affects every aspect of an individual’s life.”

Multiple Sclerosis 2002: A New Vision

This overview for our first issue of the new year was written by June Halper, MSN, ANP, FAAN, one of the founding editors of this newsletter.

MS is a disease of the central nervous system that has a far-reaching and variable impact on adults ranging in ages from 15 to 60 years. It can have profound physical, social, and psychological consequences for individuals and their families. As a disease, MS has evolved from the mysterious “crippler of young adults” to one with a new vision—one of empowerment, hope, and wellness. This profound change in outlook is due, in no small measure, to the advent of disease-modifying therapies that may alter the course of MS, maintain and sustain quality of life, and change the perception of MS to one of “yes I can.” In addition, the image of MS has changed in light of new models of care that have emerged during the latter part of the 20th century. These models range from those centered around community physicians, advanced practice nurses, rehabilitation specialists, and counselors to the comprehensive care team found within MS centers or in MS networks within the community.

The Comprehensive Care Team

The comprehensive care team in MS consists of a well-informed individual with MS and his or her family or care partners; a neurologist and other physicians, such as internists, urologists, gynecologists, orthopedists, opthalmologists, and physiatrists; and nurses, social workers, rehabilitation professionals, psychologists and neuropsychologists, recreational therapists, attorneys,
and clergy. This interdisciplinary team evaluates each person and develops a plan of care that reflects individual function using the person’s input. This plan of care reaches beyond the walls of the center or clinic into homes, workplaces, and places of recreation to enable complete and independent functioning and a full quality of life. This dynamic care plan reflects the ever-changing health care, social, and emotional needs expressed by the person with MS.

MS is diagnosed and treated by a neurologist who is faced with a number of challenges: medical management of the person, individual and family communication, collaboration with the MS team, and responding to the dynamic nature of the person’s condition. Just as there are many more “tools” available today in MS care, there are also many more obstacles; they include managed care, a changing economic climate in the United States and Canada, and more complex treatment protocols that require the assistance and support of other team members, including the individual and his or her family.

Nursing services in MS rely on providing information so that individuals receiving care can make informed decisions. Nursing care is provided in a variety of settings and by a wide range of nursing professionals, including nursing assistants, clinical nurses, advanced practice nurses, as well as the care provided by the family or significant others.

During the past decade, a greater understanding of MS has emerged, leading to better therapies, different challenges for individuals and their families, and increased responsibilities for nursing professionals. Constantly expanding nursing services include “hands-on” care, education, skills development, advocacy, case management, motivational support in complex protocols, as well as teaching and promoting sustained adherence in important self-care activities, such as self-injection, bladder management, spasticity control, and exercise. It is important to assist the person with MS in leading a productive life, in communicating with his or her family and health care providers, and in following a wellness-oriented and productive lifestyle.

Physical therapists work with people to improve strength, balance, and gait; to help increase muscle tone, enhance coordination and ambulation using assistive devices and rehabilitative techniques; and to promote compensation for sensory loss. In addition, physical therapists provide persons with MS with the opportunity to use adaptive equipment suitable to his or her individual level.

Occupational therapy involves the use of adaptive equipment and an exercise program, mainly for the upper extremities. The therapist concentrates on the person’s activities of daily living and prior level of functioning, either vocationally or as a homemaker or student. Occupational therapy goals are consistent with those of the interdisciplinary team but are specific to maximal independence. Whenever possible, occupational therapists treat symptoms, such as tremor and ataxia, with adaptive equipment and compensatory techniques to reduce dysfunction and promote independence. Cognitive issues also are addressed in occupational therapy, especially as they affect one’s ability to perform self-care routines or manage activities of daily living.

The speech and language pathologist focuses on a variety of communication and potential medical problems in MS, such as swallowing difficulties and breathing problems. Symptoms such as dysarthria and poor voice projection can be addressed with a structured exercise program and regularly scheduled care. Communication patterns and, thus, the person’s self-esteem are improved. Dysphagia has been recognized recently as a serious and even life-threatening problem in MS, and those affected may be subject to silent aspiration with resultant pulmonary complications. Therapy focuses on strengthening accessory muscles and instructing individuals and their families to use alternate strategies for safe swallowing.

Counseling and supportive services may be provided by a social worker or a clinical psychologist and are designed to alleviate the stress of chronic illness. These services attempt to promote improved coping with the changes imposed by MS related to work, financial status, child care, relationships, and emotional responses by the

**MS Exchange to Become the Official Newsletter of the Consortium of MS Centers**

Our next issue of *MS Exchange* will take on a completely new look. In keeping with the multidisciplinary focus of the Consortium of Multiple Sclerosis Centers (CMSC), we are revamping our format to include articles from individuals involved in various fields of care. An advisory group has been formed that will feature representatives from a number of disciplines. The group’s goal will be to structure an informative newsletter that serves as a valuable method of communication for all members of the CMSC.

This exciting development will ensure that *MS Exchange* keeps pace with the rapidly expanding and evolving field of MS care and treatment. We plan to continue to report on our successes as well as to feature news, articles, and activities of the International Organization of Multiple Sclerosis Nurses (IOMSN) in a pullout section of the newsletter.

As directors of the editorial board, we invite everyone to watch for the newly renovated *MS Exchange*!

Colleen Harris, RN, BN, MN Linda Morgante, RN, MSN, CRRN

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*continued on page 9*
Document Defines Role of MS Nurses in the UK

On April 25, 2001, during MS Awareness Week, a set of guidelines entitled “Specialist Nursing in MS—the Way Forward: key elements for developing MS-specialist nurse services in the UK” was released. The goal of the project, which was sponsored by an unrestricted grant from major pharmaceutical companies, was to describe, define, and develop MS-specialist nurse services in the United Kingdom.

The report describes the role of the MS nurse, identifies the resources required to initiate such a position, assesses cost implications, determines development requirements, considers different models of care, and sets standards of clinical operation. The hope is that the project will improve care for persons with MS in the United Kingdom both by raising awareness about MS nurses’ responsibilities and by increasing the number of MS nurses. The document is available on the Internet at the MS Research Trust Web site (www.mresearchtrust.org.uk).

MS Nurses Are Integral to Managing Severe Spasticity

According to L. Jarrett, a Spasticity Management Clinical Nurse Specialist, MS nurses play an integral part in the management of severe spasticity in people with MS. Intrathecal baclofen therapy (ITB) is one method that nurses use to manage severe lower limb spasticity. The author outlined some of the responsibilities that MS nurses have when implementing and maintaining ITB therapy.

For ITB to be successful, it requires the completion of many stages, including spasticity assessment, an ITB trial, pump implantation, discharge planning, a 24-hour help line, ongoing pump refills, and dose titration clinics; MS nurses play a unique and an important role during each step. Further, MS nurses are involved with minimizing sensory stimuli to reduce flexor spasms, maximizing postures in lying and sitting to promote comfort and reduce pain, providing drug education, and determining whether spasticity is having an impact on the person’s sexual functioning and/or emotional well-being.

Maintaining an ongoing relationship with the patient allows the nurse to offer advice, support, and referrals to other specialists.
What Affects Quality of Life in Persons With MS?

Marital status and income do not appear to have a significant impact on quality of life for persons with MS, according to a German study conducted by researchers from the University of Hamburg, Germany. In a survey that combined the Hamburg Quality of Life Questionnaire in Multiple Sclerosis with inquiries regarding various sociodemographic factors, marital status and income were not major influences on quality of life in this German population.

The researchers, led by Heesen and colleagues, received 434 replies from persons with MS (70% women, mean age: 44, mean disease course: 10 years). While 22% of the respondents lived alone, their answers indicated no differences in quality of life when compared with the replies from persons with families or from those living as part of a couple. Results did show that quality-of-life scores were significantly higher for women than for men. Also, participants with more education (13 years of school or more) tended to rate their quality of life as better than did those with less education.

It should be noted that quality of life was found to be significantly greater for those with MS who were employed. However, 27% were paying rent of less than 750 Eurodollars per month, which suggested that these respondents had a lower income level, yet there was no consistent corresponding drop in quality-of-life scores.

Based on all of the study data collected, the authors concluded that marital status and income seemed to have only a minor influence on quality of life for those with MS.

When Standard Treatment Is Not Enough

A poster presented by Jeannine Christopherson, RN, BScN, at the MS International Federation International Conference 2001 in Australia last September outlined a challenging case study. It involved a 40-year-old man with progressive-relapsing disease whose condition was being managed by an MS clinic nurse in Edmonton, Alberta, Canada. His Expanded Disability Status Scale score was 6.5 and his symptoms included spasticity, neuralgic pain, neurogenic bladder and bowel, and depression. He was married with children and employed full time.

Both interferon treatment (six months) and mitoxantrone therapy (11 months) needed to be discontinued because of a significant drop in platelets. While he required narcotics to control pain, the side effects caused constipation. As his disease progressed, his despondency increased. Because the prescribed antidepressants lowered his libido, this individual chose not to adhere to regular treatment although he did take them intermittently for four years. He also refused to attend personal and family counseling, which were recommended because of the many difficulties that he faced in his day-to-day life.

Despite his continued despondency, he remained in close contact with his clinic nurse. They met three times per year and spoke at least once a week. The nurse experienced much frustration and mixed emotions since drug treatment could not be continued and because the patient refused formal counseling. In this particular case, the nurse was able only to provide emotional support through listening and to guide the patient with his medication regimen. In doing so, the nurse remained objective and supported the patient’s decisions, even though they were contrary to the nurse’s recommendations.

Over a three-year period, the person with MS gradually improved his ability to cope as observed by fewer telephone calls to the nurse and as noticed by an elevation in mood and a lessening of despair during the contacts that did occur. While the search for viable treatment in this case is ongoing, the continual contact with the nurse who provided a caring ear appears to have alleviated some of his frustration.
The Nurse Consultant: A Pivotal Player in MS Care

The recent advances in MS drug therapies coupled with the variable course of this disorder are shaping the role of the MS nurse consultant in Australia. A clinical update that appeared in the September 2001 issue of the *Australian Nursing Journal* outlined the challenges facing these care providers.

The authors described the general functions of the MS nurse consultant as: being pivotal in initiating and maintaining immunotherapy for the person with MS, both in the hospital and in the community setting; assisting in coordinating drug and other related trials; and providing education in the administration and maintenance of drug therapy. In caring for a person with MS, today’s nurses must consider not only the disease symptoms, but also the emotional and psychological implications of a disorder whose manifestations are random and unpredictable and whose prognosis may vary from slight ailment to severe disability.

Specifics of the nurse consultant role were discussed within the context of a three-pronged approach to MS disease management: symptom control; disease-modifying therapies; and acute-relapse treatment. For symptom control, the nurse needs to be aware that addressing one symptom may adversely affect another (eg, a drug that manages spasticity may exacerbate drowsiness and fatigue). Here, the nurse can help the person with MS to establish priorities for symptom relief and can provide guidance in preventative measures for symptom management.

Regarding disease-modifying therapies, the nurse consultant should emphasize that available medications are treatments, not cures, with the goals being to reduce the incidence of exacerbations and to delay, and not necessarily to prevent, increasing disability. The MS nurse needs to provide support and encouragement for the long-term use of these drugs, and offer strategies for dealing with side effects. When treating an acute relapse, the nurse needs to ensure that the individual with MS realizes that this medication has a limited purpose (ie, to shorten the relapse length) and will not change the progression of the disease.

The authors stressed the importance of being sensitive to MS issues and building a trusting relationship with the person having this disorder, so that ongoing assistance can be sustained as long as necessary.


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Long-Term Study of Abnormalities on MRI and Disability from Multiple Sclerosis

For many years, neurologists and those in related areas have used magnetic resonance imaging (MRI) scans of the brain to help in making the diagnosis of MS. Although no single test is definitive, the presence of such abnormalities as white-matter lesions in the cerebrum on MRI is linked with a greater risk of developing MS.

Now, however, a new long-term British study of the relation between such abnormalities on MRI and the extent of disability from MS further supports the idea of an association. The study, which appeared in a recent issue of *The New England Journal of Medicine*, was performed by researchers led by Dr. Peter Brex at the Institute of Neurology in London. The principal goal of this study was to assess the strength of the relationship between volumes of lesions on previous MRI scans and the extent of disability after the passage of a number of years.

In a serial MRI study that used radio waves and magnetic fields to capture cross-sectional images of the brain, 71 individuals with isolated syndromes that suggested clinical MS were reevaluated after a mean of just over 14 years. Specifically, such isolated syndromes involve optic neuritis, the brain stem, or the spinal cord, and persons with them could develop MS at any point in time thereafter from months to many years. Kurtzke’s Expanded Disability Status Scale (EDSS) was used to measure the level of disability.

Forty-four of 50 people (88%) with abnormal results on MRI at presentation and four of 21 individuals (19%) with normal results on MRI developed clinically definite MS.
In individuals who present with isolated syndromes that suggest MS, the increases in lesion volume on MRI of the brain in the first five years correlate with the extent of long-term disability resulting from MS. Because this relation is only moderate, the authors observed that the volume of the lesions alone may not be a sufficient basis for deciding whether to use disease-modifying treatment.

Some 98% of those with MRI abnormalities at baseline exhibited either clinical or radiologic evidence of multiphasic disease. It is thought that this long-term follow-up study confirms that white-matter lesions on MRI of the brain in young adults with isolated syndromes are due to MS in nearly all cases.

At 14 years, the EDSS score correlated significantly with volumes of lesions on MRI at all previous time points. The authors interpreted this as indicating that the volume of lesions at any time contributes to the development of later disability. Although numbers of lesions show broadly similar correlations, they are less reliable than volumes as a measure of disease progression. This is because such factors as enlargement and confluence of lesions cannot be accounted for and lesion sizes vary.

According to the authors, a relation between clinical features in the early years of MS and long-term disability has been identified by natural history studies.

In the first two to five years after the development of an isolated syndrome, both MRI and clinical measures of disease activity are important in the long-term prognosis for disability in persons with MS.

This is suggested by the MRI study under discussion as well as by previous clinical studies.

Aside from the total volume of the lesions, there are other pathologic features that are likely to contribute to disability. Such features include spinal cord disease, axonal loss in lesions, abnormalities in the normal-appearing tissues, and diffuse atrophy.

The current study demonstrates that lesion volume on MRI in individuals with isolated syndromes and early MS (which is defined as the first five years of the disease) is of prognostic value in evaluating the risk of future disability. The authors stressed that because the correlations are only moderate, lesion volume alone should not be used in deciding whether to employ disease-modifying treatments for affected individuals. The results do seem to suggest a potential long-term clinical benefit of treatments that suppress the formation of lesions early in the course of the disease. However, the study authors caution that the mechanisms underlying the observed relation between clinical and MRI data are uncertain.

INTERESTED IN SHARING YOUR KNOWLEDGE WITH THE WORLD? JOIN THE IOMSN!

The IOMSN is the only organization dedicated to the education of MS nurses around the world. If you wish to join the IOMSN, you can access it on the World Wide Web at www.iomsn.org, or contact the organization at:

IOMSN
c/o Bernard W. Gimbel MS Comprehensive Care Center
718 Teaneck Rd
Teaneck, NJ 07666
(201) 837-0727

According to the authors, a relation between clinical features in the early years of MS and long-term disability has been identified by natural history studies.
individual and his or her family. Attention to the psychological implications of MS is as vital a component of comprehensive care as any other service or medication that may be prescribed.

In many comprehensive care centers, there are neuropsychologists to diagnose cognitive changes due to MS; a vocational counselor to assist persons in evaluating their employment status and vocational skills; and a recreation specialist to help develop new ways of relaxing and enjoying more in life and remaining physically fit during these activities.

**The Consortium of Multiple Sclerosis Centers**

The Consortium of Multiple Sclerosis Centers (CMSC) was organized in 1986 under the auspices of neurologists who specialize in MS. Since that time, the CMSC has grown to over 200 member centers in the United States, Canada, South America, and Europe, along with numerous individual members who are neurologists, nurses, psychologists, and rehabilitation professionals. In addition, there are corporate sponsors and such nonprofit partners as the Latin American Committee for Treatment and Research in MS (LACTRIMS), the Latin American counterpart of the CMSC. The CMSC/North American Research Committee on MS (NARCOMS) registry seeks to identify treatment trends and demographic characteristics of persons with MS throughout the world. The CMSC Web site (www.mscare.org) is a prime source of education and information and the *International Journal of MS Care* is both a print and online journal focusing on patterns of care and clinical research (www.mscare.com). The mission of the CMSC is to be the preeminent organization of MS professionals, who, through collaborative and interdisciplinary approaches, lead the development and dissemination of scientifically based knowledge regarding MS clinical care.

**A New Vision**

Although outcomes of immunomodulating therapies have added disease modification to the MS treatment regimen, the mainstays of care remain acute, symptomatic, and rehabilitation services. The new vision of MS incorporates a wellness approach to identify and prevent secondary and tertiary problems of the disease.

Another facet of the new vision of MS is the empowerment model, the philosophy of proactive involvement in managing MS. This model requires that both the individual and the professional keep current about MS care and research, maintain a professional network in the MS community, understand and use current technology in MS care, and develop a personal philosophy of empowerment. Individual and family education is a critical element in this model. It is vital that the person with MS and the family understand the disease and its impact; recognize and accept realistic treatment options; and use appropriate programs, services, and information resources. Advocacy is an important component of empowerment in that it guarantees the individual’s full access to services, programs, and treatments.

The new vision of MS has led to better treatment options for the disease, new models of care, expanding networks, greater possibilities, renewed hope for control of the disease process, and ultimately, in the not-too-distant future, a cure.

**Literature Monitor/News Roundup**

**Predictors of Adherence—and Nonadherence—to Glatiramer Acetate Treatment**

High levels of self-efficacy and hope, as well as physician support and no history of immunomodulator use are predictors of adherence to glatiramer acetate (Copaxone®) treatment among individuals with MS, according to a study recently reported in the *Journal of Neuroscience Nursing*. Because glatiramer acetate treatment requires daily subcutaneous injections, nonadherence can be a problem. Based on these study results, health care providers may be able to prevent treatment lapses or failures.

The authors selected individuals from two separate databases, one being an MS registry, and the other for MS support services. Exclusion criteria included use of multiple immunomodulating drugs and an inability to complete the data collection instruments. Booklets containing four instruments (the MS Self-Efficacy Control and Function Subscales, Rosenberg Self-Esteem Scale, Herth Hope Index, and Performance Scale) and sociodemographic data sheets were mailed to 1,200 individuals. Of the 594 participants who completed and returned the booklets, 341 had relapsing-remitting MS; 225 were treatment adherent, and 116 were nonadherent. Adherence was defined as daily therapy with subcutaneous glatiramer acetate continuously for at least one year, whereas nonadherence was defined as treatment that stopped after less than one year.
To form their study hypotheses, researchers reviewed the medical literature and found that the authors of one study reported that self-efficacy is the highest predictive factor of perseverance in a new behavior. Hope, which has been defined as any expectation that a goal will be realized, has been reported to be a primary motivator that is needed for action. Two other variables that the study authors hypothesized might be linked to adherence to treatment were self-esteem and level of disability.

The researchers conducted logistical regression analysis of the relationship between psychological, biophysical, and sociodemographic variables, and adherence category. Of the four study hypotheses, two were found to be significant predictors of adherence: self-efficacy and hope. The researchers concluded that self-esteem and level of disability were not predictors of compliance.

As a result of the analysis, two additional variables emerged as predictors of treatment compliance. The perception that the physician was the most supportive of the treatment \((P = .02)\) occurred more often in the adherent group (60.4%) than in the nonadherent group (45.7%). Persons with no history of immunomodulator use were 1.75 times more likely to be compliant \((P = .03)\) than those with such a history.

To help ensure that individuals adhere to glatiramer acetate treatment, health care practitioners should send a clear message of support for the treatment. This is especially important for persons who have already tried immunomodulating therapy. For those with a history of noncompliance, measures to bolster self-efficacy may prove helpful. These include teaching skills for self-managing a chronic illness, identifying realistic expectations offering feedback and praise, and instilling self-confidence.


### From the subjects’ responses, the researchers concluded that the process of gaining an understanding of relapsing MS and available treatments is a complex and long-term one.

Fear of the unknown may cause people with MS to be reluctant to start interferon beta-1a therapy. This is unfortunate, because treatment can delay the development of the physical disability that naturally occurs with untreated relapsing MS. To help persons with relapsing MS better understand what they might experience, Miller and Jezewski conducted serial interviews with 15 persons who were receiving interferon beta-1a treatment.

From the subjects’ responses, the researchers concluded that the process of gaining an understanding of relapsing MS and available treatments is a complex and long-term one. Areas of concern that were identified during the analysis included insurance limitations, coping with self-injection, and understanding side effects. Financial assistance, injection training, and telephone support were made available to help alleviate these concerns. For most subjects, side effects diminished over time. Good social support was helpful, especially for persons afraid of self-injection.
Most of the study subjects said that their condition improved after beginning interferon beta-1a treatment. They reported having fewer and milder disease exacerbations, and feeling less fatigued. Interferon beta-1a gave subjects a sense of control over MS and restored their sense of optimism about their future.


**Aggressive and Multidisciplinary Symptom Management Optimizes Treatment**

Optimizing treatment for the person with MS requires that the nurse have a keen understanding of the multiple symptoms that the individual with MS can experience. Many individuals, when they think of MS, still envision it as a disease characterized by gross motor problems. In fact, there is a whole array of symptoms that can have a severe impact on daily functioning and quality of life. These include primary symptoms such as fatigue, spasticity, genitourinary disorders, bowel and sexual dysfunction, and cognitive changes, as well as problems such as depression and sleep disorders that occur secondary to another symptom. Tertiary problems, such as social dysfunction and unemployment, may also result.

Many health care providers have seen firsthand the tremendous impact that fatigue has on the person with MS. Far from a benign condition, fatigue has been consistently described as the most disabling of all MS symptoms. It affects 95% of persons with MS and can arise as a direct result of MS, be depression-related, or both. MS fatigue generally occurs in the afternoon and lasts about six hours, whereas depression-related fatigue tends to be present upon waking and lasts throughout the day. Interventions include keeping cool, resting, exercising, and employing energy-conserving techniques. Fatigue caused by depression can be managed with counseling and oral antidepressants. MS-related fatigue also can be managed with an antiviral agent or a mild central nervous system stimulant.

Spasticity usually affects the limbs and is triggered by infection, disease relapse, body positioning, skin breakdown, and a full bowel or bladder. Effective interventions include range-of-motion and stretching exercises; relaxation techniques; such devices as toe or finger spreaders; wrist, foot, and hand orthoses; and medications.

Although bladder dysfunction affects 80% of people with MS, it often goes untreated. Failure to store, failure to empty, or both are the most common problems. Interventions include avoiding caffeine, aspartame, alcohol, and other diuretics. Scheduled voiding, the Credé technique, biofeedback, Kegel’s exercises, aerobic exercise, and pelvic muscle stimulation may be beneficial. Catheterization may be needed, and bladder reconstruction surgery may be indicated.

Bowel dysfunction, such as constipation and involuntary bowel emptying, affects 60% of individuals with MS. Constipation may be a neurogenic problem, but it also can be caused by medication, inadequate dietary fluid and bulk intake, inactivity, and spasticity. Timed bowel emptying, proper diet and fluids, exercise, and laxatives and anticholinergics are effective interventions.

Sexual dysfunction affects 90% of men and 70% of women with MS. Erectile dysfunction is the most common primary problem of men. Women report fewer or less intense orgasms and reduced vaginal lubrication. Both genders report decreased libido and altered genital sensation. Fatigue and bladder and bowel dysfunction lead to secondary sexual dysfunction. Such social, cultural, and psychological issues as poor body image cause tertiary dysfunction. Simple interventions include decreasing fluid intake and emptying the bladder and bowel prior to sexual activity, and timing medications so they will not interfere with function. Erectile dysfunction can be managed with sildenafil, penile injections, urethral suppositories, a penile vacuum, or surgical implants.

Memory and other cognitive impairment affect 50% of persons with MS. Assessment and rehabilitation must be aggressive. Teaching affected persons to use such compensatory strategies as making lists and using tape recorders are helpful.

Symptom management requires a thorough medical evaluation and history. Diaries of activities, bladder and bowel habits, sexual activity, and a medication history are useful tools. Effective communication between persons with MS and their families, friends, and health care providers is vital. By aggressively managing symptoms, nurses can greatly improve the quality of life for persons with MS.

CONTINUING EDUCATION CONFERENCE CALENDAR

March 16–19, 2002
34th Annual Meeting of the American Association of Neuroscience Nurses. Location: Chicago. Contact: AANN, 4700 West Lake Ave, Glenview, IL 60025-1485; (847) 375-4733; fax: (847) 375-6333; Web site: www.aann.org.

April 13–20, 2002

June 5–9, 2002
Annual Meeting of the Consortium of Multiple Sclerosis Centers. Location: Baltimore. Contact: Leah Temena or Tina Trott, Consortium of Multiple Sclerosis Centers, c/o The Bernard W. Gimbel MS Center, 718 Teaneck Rd, Teaneck, NJ 07666; (201) 837-0727; fax: (201) 837-9414; e-mail: info@mscare.org; Web site: www.mscare.org/meeting/2002.html.

June 22–26, 2002

October 9–12, 2002
2nd Congress of the Latin American Committee for Treatment and Research in Multiple Sclerosis. Location: Monterrey, Mexico. Contact: Merced Velazquez, MD, by e-mail: mchvelazquez@infosel.net.mx or Victor M. Rivera, MD, at 6560 Fannin, Suite 1224, Houston, TX 77030; (713) 798-7707; fax: (713) 798-6273; e-mail: vrivera@bcm.tmc.edu.

October 13–16, 2002
127th Annual Meeting of the American Neurological Association. Location: New York City. Contact: Lori Anderson, ANA, 5841 Cedar Lake Rd, Suite 204, Minneapolis, MN 55416; (952) 545-6284; fax: (952) 545-6073; e-mail: lorijanderson@msn.com; Web site: www.aneuroa.org.

November 2–7, 2002
32nd Annual Meeting of the Society for Neurosciences. Location: Orlando. Contact: Society for Neurosciences, 11 Dupont Circle, NW, Suite 500, Washington, DC 20036; (202) 462-6688; fax: (202) 462-9740; e-mail: info@sfn.org; Web site: www.sfn.org.

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