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Enhancing Patient Communication for the MS Nurse

Preserving Quality of Life in MS

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Counseling Points™

Preserving Quality of Life in MS

Continuing Education Information

Target Audience

This educational activity is designed to meet the needs of nurses who treat patients with multiple sclerosis (MS).

Purpose

To inform MS nurses about the factors affecting quality of life in MS and to foster discussion between nurses and patients with MS on quality-of-life issues.

Learning Objectives

Upon completion of this educational activity, the participant should be able to:

- Review findings of recent research on multiple sclerosis (MS) quality of life (QOL)
- Discuss how symptoms of MS such as depression, cognitive dysfunction, and fatigue can impact QOL
- Evaluate MS-specific instruments for measuring QOL
- Initiate discussion about QOL with patients and monitor changes over the course of the disease

Continuing Education Credit

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Approximate time to complete this activity is 45 minutes.

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welcome

Dear Colleague,

Quality of life (QOL) could arguably be viewed as the most important aspect of our care of patients with multiple sclerosis (MS). After all, what can be a higher goal for us as human beings than QOL and its many components—sharing life with family and loved ones, having a sense of productiveness and worthiness to others, feeling mentally and psychologically well, and experiencing each day unburdened by pain or discomfort?

MS can present many obstacles to achieving QOL. Countless research findings, as well as our observations as nurses, have shown that what constitutes QOL is different for each person. Each person's definition of QOL also tends to change with age and life experience, regardless of health status.

While outcomes for MS treatments used to focus primarily on tangible clinical benefits such as walking speed or reduced exacerbations, QOL has come into focus as an important component of MS clinical trials of both new and existing therapies. How does one measure and quantify such a nebulous concept as QOL? In our discussions, the expert panel of MS nurses agreed that simple and practical tools for measuring MS QOL in the standard practice setting are still lacking, although these instruments are widely used in clinical trials.

How can nurses who treat patients with MS discuss and monitor QOL? In this issue we bring QOL in MS to the level of the nurse-to-patient interaction to assist you, our colleagues, in this important and often complex evaluation. We welcome your participation in *Multiple Sclerosis Counseling Points* for 2011 and hope you benefit from this ongoing continuing education program.



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Preserving Quality of Life in MS

What could be more important—yet more nebulous—than the concept of “quality of life” (QOL)? We all want it, for ourselves and for our patients, but what is it exactly? In research on multiple sclerosis (MS) and other medical conditions, QOL has become of increasing interest over the past decade. While older studies have mainly examined whether a particular treatment works the way it is supposed to (medically centered outcomes), newer trials explore more patient-centered outcomes—how the efficacy, side-effect profile, and administration of the intervention affect the patient’s life.

MS nurses are well positioned to assess QOL among their patients. Whether this is done through formal assessment instruments or via an ongoing conversation, it is important to monitor and document the effect of MS symptoms, treatments, and other circumstances on the patient’s perception of his or her QOL.

“Quality of Life” Defined

The World Health Organization (WHO) defines QOL as “the individuals’ perception of their position in life in the context of [their] culture and value systems and in relation to their goals, expectations, standards, and concerns.”¹ The WHO definition adds that QOL is affected in a complex way by factors such as:

- physical health;
- psychological state;
- level of independence;
- social relationships;
- personal beliefs; and
- relationship to environment.¹

Other definitions have characterized “health-related quality of life” (HRQOL) as a narrower

concept encompassing the aspects of life influenced by health status.² In MS, these might include the disease-related presence of cognitive changes, fatigue, physical dysfunction, pain, visual dysfunction, emotional disturbance, and social functioning.³

A user-friendly definition is given by Motl, who describes QOL as “An umbrella term that describes a number of outcomes that are considered important within an individual’s life and can include physical, social, psychological and spiritual dimensions of one’s well-being. QOL represents a person’s judgment about how well they are living based on a broad array of domains.”⁴

In another definition by Mitchell and colleagues, QOL is described as “the sum of all sources of satisfaction (including anticipated sources) minus all threats (including anticipated threats).”⁵ Mitchell and other researchers have found that psychosocial factors, coping style, and perceived social support often have a greater influence on QOL in MS than disease variables such as weakness or extent of magnetic resonance imaging (MRI) lesions (**Table 1**).^{6,7}

Research Findings on QOL

The concept of QOL does not fit neatly into medical research protocols, in part because the way people perceive QOL often fails to follow logical patterns.⁸ That is, one might assume that a person with a severe disability or even the prospect of a debilitating disease would be unhappy and/or perhaps depressed.⁹ Classic social research studies have taught us (and history has borne out) that happiness is relative and people who “have it all” are often much more miserable than the “have-nots.” Likewise, in MS one cannot assume that QOL decreases in a linear manner as the number of symptoms or the degree of disability escalates.

Table 1. Predictors of Poor QOL in MS⁵⁻⁷

Strong Predictors

- Cognitive impairment
- Depression, demoralization
- Lack of autonomy
- Lack of support
- Chronic pain

Moderate Predictors

- Fatigue
- Anxiety
- Communication difficulties
- Bladder and sexual problems
- Rapidly progressive disease
- Low self-esteem and self-deprecation
- Comorbidities

Weak Predictors

- Long disease duration
- Forced unemployment
- Older age
- Female

This “QOL paradox” infers that perceived satisfaction with life depends more on an individual’s subjective conditions than on the objective measures determined by third parties.^{10,11}

QOL must also be put into a comparative context. In the paper “Maintaining quality of life in multiple sclerosis: Fact, fiction, or limited reality?” Vasconcelos and colleagues compared the HRQOL of people with MS with that of demographically matched healthy controls.¹¹ Their findings showed that perceived HRQOL levels of patients with MS in the first half of their disease course (those with relatively mild impairment) were consistently and significantly lower than those of controls. These authors argued that “it makes little sense to assess HRQOL perceptions without a healthy comparative benchmark.” They also noted that measurements of HRQOL must be evaluated among people with various levels of disability in order to put clinicians’ expectations of patients’ responses into perspective.¹¹

Instruments Used for Measuring QOL

Table 2 summarizes a number of instruments for measuring QOL and related concepts in MS. Most of these tools ask patients to self-assess their life satisfaction (general or overall well-being), emotional or psychiatric symptoms such as anxiety or depression (cognitive component, evaluation of emotional feelings), symptoms of the disease (such as pain and fatigue), and the functional impact of the disease (such as ambulatory ability, self-care, occupational performance, and social and family participation).¹² Measuring HRQOL offers a better understanding of the impact of disease on the patient’s life than traditional clinical measures such as the Expanded Disability Status Scale (EDSS) or MRI findings.

Despite a large variety of tools available for measuring and quantifying QOL in MS, conversations with MS nurses have suggested that these instruments do not always find their way into clinical practice, especially for routine office visits. Time constraints are a major reason formal QOL measures are avoided, combined with the strain and fatigue they place on patients when multiple forms and tests are requested during an already long day of medical appointments. To address these obstacles, neurology clinics may develop secure ways for patients to complete the QOL assessments online in their own time, with the responses feeding directly into the medical record, or simply provide printable copies from their websites that patients can complete at home and bring to their appointments.

Impact of MS Symptoms on QOL

MS symptoms are primary determinants of QOL. Even so, QOL findings often do not correlate directly with measures of MS disease status such as the EDSS or the MS Functional Composite (MSFC).⁸ A review of 83 English-language studies with QOL data in MS showed that low HRQOL ratings correlated with physical disabil-

Table 2. Tools for Measuring QOL and Related Concepts¹³⁻²⁰

Assessment Name	What It Measures	Administration Details	Source/Reference
MSQOL-54 ¹³	Cognitive function; sexual function and satisfaction; energy; pain; social function	11 to 18 minutes to complete; 54 questions; self-administered	National MS Society www.nationalMSSociety.org
MSQLI ¹⁴	SF-36; fatigue; pain; sexual function; bladder and bowel issues; visual function; cognitive, emotional, and social function	Comprehensive; consists of 10 individual scales; NMSS estimates 40 minutes to administer	National MS Society www.nationalMSSociety.org
Fatigue Severity Scale (FSS) ¹⁵	9 quantitative questions on fatigue severity	Quick; self-administered; higher score = higher fatigue	Krupp LB, et al. <i>Arch Neurol.</i> 1989;46:1121-1123.
Beck Depression Inventory (BDI) ¹⁶	Severity of depression (sadness, pessimism, loss of pleasure, etc.)	21 multiple-choice questions; self-administered or by professional	Beck AT, et al. Beck Depression Inventory-II (BDI®-II). http://pearsonassess.com
Hamilton Rating Scale for Depression (HAM-D) ¹⁷	Depressed mood; feelings of guilt; suicidal tendencies; insomnia; etc.	17 multiple-choice questions; self-administered or by professional	Hamilton M. <i>J Neurol Neurosurg Psychiatry.</i> 1960;23:56-62. Available online through various sources.
Functional Assessment of Multiple Sclerosis (FAMS) Quality of Life Instrument ¹⁸	Perceptions of mobility and QOL (symptoms, emotional well-being, depression, general contentment, fatigue, social well-being)	59 items; 20 minutes to administer	Cella DF, et al. <i>Neurology.</i> 2006;47(1):29-39.
MS Impact Scale-29 (MSIS-29) ¹⁹	Physical and psychological impact of MS	29 items; created for crossover from research to practice	National MS Society www.nationalMSSociety.org
Lawton Activities of Daily Living Scale ²⁰	Ability to perform everyday activities (e.g., use the phone, shopping/food preparation, housekeeping, take medications, manage finances)	Self-administered; 10 to 15 minutes to complete (originally geared toward the elderly)	Lawton MP, <i>Gerontologist.</i> 1969;9:179-186. Available online through various sources

NMSS=National Multiple Sclerosis Society; QOL=quality of life.

ity, mental health problems, bladder and sexual problems, a long duration of disease, a severe disease course, fatigue, unemployment, and a family history of MS.²¹

Historically, studies on the impact of MS have focused heavily on medically oriented outcomes such as mobility. However, more recent data show that fatigue, sleep dysfunction, cognitive function, and psychosocial factors may play an even bigger

role in how people with MS perceive their QOL (Table 3).²²

Depression and Psychiatric Symptoms

People with MS have a higher burden of psychiatric symptoms compared with healthy age- and sex-matched controls. In 2009, Kern and colleagues found higher psychological distress even among patients with early MS who had minimal or no neu-

Table 3. MS Symptoms and QOL²²

Symptoms

- Motor and sensory dysfunction
- Bowel and bladder dysfunction
- Sexual dysfunction
- Cognitive impairments
- Mood disorder/psychosis
- Fatigue

Disease-specific Issues

- Often diagnosed at young age
- Unpredictable course
- No cure as yet
- Treatments have detriments such as invasiveness, side effects, variable efficacy, high cost

QOL=quality of life.

rologic disability compared with control subjects.²³ Rates of major depression are significantly higher among people with MS than in the general population, with a lifetime prevalence as high as 50%.^{24,25} This is higher than the rate observed in other chronic diseases, even conditions such as amyotrophic lateral sclerosis.²⁶

In a recent study by Jaracz and colleagues, depression was the main predictor of QOL after adjusting for other factors.²⁷ These authors suggested that treating mood disturbances might significantly improve QOL for people with MS. Nurses should be aware of the high risk of depression among patients at all stages of the disease. Patients and family members should be made aware of the common symptoms of depression and encouraged to discuss any warning signs with a clinician.

Cognitive Dysfunction and QOL

Cognitive dysfunction affects as many as 50% of people with MS.²⁸ Symptoms may present soon after diagnosis but are often overlooked.²⁹ Research on how cognitive impairment impacts QOL has been somewhat conflicting, but most studies support the assumption that cognitive dysfunction negatively impacts QOL, especially as it relates to reduced work fulfillment and difficulty with social and family interactions.^{30,31}

Fatigue and QOL

MS-related fatigue is a highly debilitating condition that interferes significantly with daily activities. Fatigue is considered the most common MS symptom (affecting up to 75% of patients) and is also one of the greatest contributors to impaired QOL.^{15,32} Fatigue impacts QOL by reducing physical stamina and interfering with work, family, leisure, and social activities, thereby leaving the person feeling unfulfilled in his or her roles.³³ Because fatigue is an “invisible” symptom of MS, it may lead to conflicts in personal and work relationships because others may not recognize its impact and severity.³⁴ Fatigue is closely linked to a person’s sense of control over MS and psychological well-being, so helping to increase a person’s sense of control over fatigue could also help to improve QOL.^{35,36}

Interrelationship of MS Symptoms

Pain in MS is believed to be related to nerve damage due to exposed myelin or potentially to the underlying inflammatory process.³⁷ In a study comparing pain levels among women with MS and women without MS, Newland et al found that increased pain tended to heighten other key symptoms of fatigue, depression, and sleep disturbance in both groups. In both groups, these factors contributed to decreased QOL.³⁸ In MS, depression, anxiety, cognitive function, fatigue, and other symptoms are often closely interrelated. Thus, pain and/or depression lead to sleep disturbance, which exacerbates fatigue, creating a vicious cycle of more fatigue and increased depression.^{38,39}

Likewise, some medications used in MS to alleviate symptoms such as spasticity have the unwanted effect of increasing fatigue, concentration difficulties, or depression.⁴⁰ This highlights the importance of individually tailoring each patient’s medication regimen with QOL goals in mind. This may mean tailoring medication dosages or administration schedules in an effort to minimize side effects.⁴⁰

Aspects of MS Treatment Affecting QOL

Several pharmacologic and nonpharmacologic interventions used in MS have been shown to provide sustained improvements in QOL for patients. A recent study on the effect of glatiramer acetate (Copaxone[®]) in MS QOL was undertaken by Jongen et al among 197 subjects with relapsing MS.⁴¹ Of the study population, 91 had prior exposure to immunomodulatory drugs and 106 were treatment-naïve at baseline. QOL was measured at baseline, 6 months, and 12 months using the Leeds QOL scale along with measures for fatigue and depression. Treatment with glatiramer acetate resulted in significantly improved QOL scores in the treatment-naïve group ($P < 0.001$) at 6 and 12 months, but not in the pretreated group. Similarly, fatigue scores were also significantly decreased in this group at the 6- and 12-month follow-ups. After 1 year, 43% of the treatment-naïve group demonstrated improved QOL while receiving glatiramer acetate treatment.⁴¹

Other studies have examined the effects of interferon (IFN) therapies for MS on HRQOL. Lily and colleagues assessed QOL among 210 subjects with relapsing MS treated with either intramuscular IFN beta-1a (Avonex[®]), subcutaneous IFN beta-1a (Rebif[®]), or subcutaneous IFN beta-1b (Betaseron[®]).⁴² All IFN treatments were associated with significantly increased HRQOL within 1 month, and it remained elevated throughout the study course. Those subjects with poor QOL scores at baseline showed the greatest benefit from treatment, while those whose treatment was stopped due to progression, lack of efficacy, or side effects had significantly lower QOL scores on treatment.⁴² Another study by Jongen involving intramuscular IFN beta-1a (Avonex[®]) showed significantly improved physical and mental QOL scores on the MSQOL-54 scale over 2 years of treatment.⁴³

Rudick and colleagues examined HRQOL data

from more than 2,000 patients enrolled in the AFFIRM and SENTINEL clinical studies of natalizumab (Tysabri[®]).⁴⁴ In the AFFIRM study, patients received natalizumab or placebo, while those in the SENTINEL trial received either IFN beta-1a (Avonex[®]) plus natalizumab or Avonex[®] plus placebo. QOL was evaluated using the Short Form-36 (SF-36) and a visual analog scale at 6 months, 1 year, and 2 years. Baseline SF-36 scores among the subjects were observed to be lower than those seen

Several pharmacologic and nonpharmacologic interventions used in MS have been shown to provide sustained improvements in QOL for patients.

in the general population. Treatment with natalizumab significantly improved the physical and mental component summaries of the SF-36 at 2 years in the AFFIRM trial. The investigators reported that “Natalizumab-treated patients in both studies were more likely to experience clinically important improvement and less likely to experience clinically important deterioration on the SF-36 [Physical Component Summary].”⁴⁴

Nonpharmacologic Approaches for Improving QOL

Exercise is well known to improve well-being in the general population as well as in people with chronic diseases. Physical activity has been shown in clinical trials to improve QOL in MS; in addition, these improvements have been observed anecdotally at many MS centers.

Recent research by Motl explored the idea that exercise improves QOL in MS by influencing factors such as disability, fatigue, and mood.⁴⁵ A sample of 292 subjects with MS wore accelerometers for 1 week to measure their physical activity levels and

completed assessments of QOL, disability, fatigue, mood, pain, self-efficacy, and social support. Subjects with higher activity levels reported lower levels of disability, depression, fatigue, and pain, and higher levels of social support and self-efficacy. Likewise, those who had lower scores for depression, anxiety, fatigue, and pain—and higher scores for social support and self-efficacy—were found to score higher on QOL measures.⁴⁵

Other effective ways to reduce stress from illness and thereby increase QOL is through the practice of meditation and/or mindfulness training. Grossman and colleagues compared the effects of an 8-week mindfulness training program versus usual care among 150 people with either relapsing or secondary-progressive MS, and measured HRQOL, depression, and fatigue at baseline, post-intervention, and after 6 months.⁴⁶ Secondary outcomes included anxiety and personal goal attainment. Mindfulness training was popular among the intervention group, with high attendance (92%) and a low dropout rate (5%). Compared with usual

care, the training significantly improved the primary outcomes ($P<0.002$) at the postintervention and 6-month follow-ups. Even greater benefits were shown among subgroups of patients with clinically relevant depression, fatigue, or anxiety. The investigators noted that the study demonstrated “broad feasibility, acceptance of, satisfaction with, and adherence to” mindfulness training for patients with MS.⁴⁶

Communicating with Patients about QOL

Whether or not formal instruments are used to monitor QOL in your practice, ongoing conversation is needed about what QOL means to each individual. The patient interview should move beyond “How have you been feeling lately?” to “How has MS affected your daily life?” and “How has your *quality* of life been affected... by the disease, treatments, medication side effects, etc.” Some points to keep in mind during these conversations are provided in this section.

Look at MS within the Big Picture

People who deal successfully with MS are often able to view the disease as only one part of themselves, rather than allowing it to define them as people. Some are even able to create “spaces” in their lives that are relatively MS-free, rather than letting their condition define their every minute. A figure used in nursing education depicts MS as a huge ball in front of the person. The goal is to shrink the ball to a more manageable size, so MS becomes one aspect of life that must be dealt



with, but not the predominant aspect of the person's life. This goal is certainly more difficult for some people to achieve than for others.

Account for Changes in Life Circumstances

A person's definition of QOL inevitably changes with time and life circumstances. Those who are newly diagnosed often focus on "willing" the disease and its problems to go away, rather than looking at how they can live well with it. A young woman may mourn her inability to wear high heels because it forces her to change her self-image. The same type of adjustment often comes when a person has to begin using a cane, a walker, or a wheelchair. The physical adjustment to using this piece of equipment may be much less important than the emotional adjustment of trying not to define herself as old, weak, or disabled. As time passes, however, priorities change regardless of a person's medical condition.

A person will also face new life stresses unrelated to MS, such as the aging of parents or the challenges of raising teens. Life transitions may usher in role changes that create new stresses and influence QOL—for example, if the person with MS has to rely upon an older teen to help with injections, or a spouse for catheterization. Thus, conversations about QOL must be ongoing, dynamic, and highly individualized. Usually, this is easier if the nurse has the advantage of a long-term relationship with the patient.

Listen with Empathy

A person with MS may be affected by fatigue, visual problems, pain, or other unseen symptoms and yet hear from friends, family, or coworkers, "You look so good." The implication is that this person is not suffering and does not appear to be affected by the disease in any way. The nurse can acknowledge that this constellation of symptoms can be extremely dis-

abling for the patient. It may be beneficial for some patients to receive further evaluation from a specialist to get additional help for specific conditions.

Sometimes nonverbal cues from a patient or care partner can contribute insight into the person's situation. For example, a partner who is looking away or manipulating a cell phone during the conversation may be uncomfortable with the particular topic, (e.g., sexuality) or may be indicating a lack of support for the patient's situation. Many aspects of QOL in MS may be embarrassing or awkward for the person to discuss, particularly in the presence of a family member.

Promote Self-efficacy

Self-efficacy is defined as a person's belief in his or her ability to succeed in a situation. The degree of self-efficacy—how much control a person feels he or she has over a difficult situation—is a key determinant of how people perceive their QOL. By nature, MS tends to interfere with that sense of control because of its unpredictable course and the day-to-day variability in symptom presentation. The nurse must keep in mind that just as coping styles vary widely among individuals, not every person is equally capable of mounting a positive, "can-do" approach to battling their condition. Some people need a great deal of support, counseling, and reassurance. Self-efficacy is closely related to the degree of support the person has from family and loved ones. Those fortunate enough to have a strong and nonjudgmental support system have a better chance of feeling they have some control over their situation.

Help Establish Realistic Treatment Goals

Setting realistic treatment goals is critical to how people with MS view QOL. This does *not* necessarily mean bursting the bubble for those people who have their hearts set on experiencing a cure for MS in their lifetimes. It is possible for people with

chronic diseases to have larger, overreaching hopes and still be able to focus in on short-term, realistic goals that relate to their care. The challenge for the MS nurse is working with patients to define and understand these goals, help adjust them as necessary, and celebrate when they are achieved.

For example, one MS nurse described a patient who started on a newer form of disease-modifying therapy and had set for herself the goal of walking. Six months after starting the treatment, she was still using her motorized scooter. However, she had experienced a significant change in her dysarthria that enabled her speech to be understood much more clearly. “It crystallized for me that patients often focus on the improvement they hope for—not necessarily the improvements they get,” the nurse observed. “The patient continued on the medication, but it was necessary to help refocus her goals.” This can be done without discounting or negating a patient’s hopes, but by saying, “Let’s look at what we have accomplished on the way to that goal.”

Be Aware of Referral Options

Many of the symptoms that affect MS QOL are also the most under-treated, including depression, fatigue, and sleep disturbance. Depression in MS often responds well to treatment. Many cognitive and behavioral therapies have been studied in patients with MS and have been shown to improve parameters of QOL as well.

People who are newly diagnosed or who have been diagnosed with a progressive form of MS may be in particular need of psychosocial support. Professional help or peer support groups may be recommended to help these people adjust emotionally to the denial and anger that accompanies the diagnosis.

Conclusion

While it is impossible for the nurse to grasp all of the many nuances of MS that affect QOL, it may help to refocus patient interactions with each indi-

vidual’s QOL goals in mind. Often as clinicians we focus on the physical things that are easy to measure, without stopping to consider, or ask, what that really means to the patient. Do your patients have QOL-related needs that are left unsaid, or ignored in the pursuit of other, more tangible outcomes? Communicating with patients about QOL involves viewing MS within the “big picture” of life, listening with empathy, promoting self-efficacy, and helping patients to establish realistic treatment goals.

References

1. World Health Organization. WHOQOL: Measuring Quality of Life. Programme on Mental Health. Accessed March 3, 2011 at: www.who.int/mental_health/media/68.pdf.
2. Benito-Leon J, Morales JM, Rivera-Navarro J, et al. A review about the impact of multiple sclerosis on health-related quality of life. *Disabil Rehabil*. 2003;25:1291-1303.
3. Miller DM, Rudick RA, Baier M, et al. Factors that predict health-related quality of life in patients with relapsing-remitting multiple sclerosis. *Mult Scler*. 2003;9:1-5.
4. Motl RW, Suh Y, Weikert M. Symptom cluster and quality of life in multiple sclerosis. *J Pain Symptom Manage*. 2010;39:1025-132.
5. Mitchell AJ, Benito-Leon J, Gonzalez JMM, et al. Quality of life and its assessment in multiple sclerosis: Integrating physical and psychological components of well being. *Lancet Neurol*. 2005;4:556-566.
6. Simmons RD. Life issues in multiple sclerosis. *Nat Rev Neurol*. 2010;6:603-610.
7. Wollin JA, Fulcher G, McDonald E, et al. Psychosocial factors that influence quality of life and potential for self-management in multiple sclerosis. *Int J MS Care*. 2010;12:133-141.
8. Foley JF, Brandes DW. Redefining functionality and treatment efficacy in multiple sclerosis. *Neurology*. 2009;72(Suppl):S1-S11.
9. Brickman P, Coates D, Janoff-Bulman R. Lottery winners and accident victims: Is happiness relative? *J Personality Social Psychol*. 1978;36:917-927.
10. Albrecht GL, Devlieger PJ. The disability paradox: High quality of life against all odds. *Social Sci Med*. 1999;48:977-988.
11. Vasconcelos AG, Haase VG, Lima Ede P, et al. Maintaining quality of life in multiple sclerosis: Fact, fiction, or limited reality? *Arq Neuropsiquiatr*. 2010;68:726-730.
12. Moons P, Budts W, De Geest S. Critique on the conceptualization of quality of life: A review and evaluation of different conceptual approaches. *Int J Nurs Stud*. 2006;43:891-901.
13. Multiple Sclerosis Quality of Life-54 (MSQOL-54). National Multiple Sclerosis Society. Accessed March 3, 2011 at: www.nationalmssociety.org/for-professionals/researchers/clinical-study-measures/msqol-54/index.aspx.
14. Multiple Sclerosis Quality of Life Inventory (MSQLI). National Multiple Sclerosis Society. Accessed March 3, 2011 at: www.nationalmssociety.org/for-professionals/researchers/clinical-study-measures/msqli/index.aspx.
15. Krupp LB, LaRocca NG, Muir-Nash J, et al. The Fatigue Severity Scale: Application to patients with multiple sclerosis and systemic lupus erythematosus. *Arch Neurol*. 1989;46:1121-1123.
16. Beck AT, Steer RA, Brown GK. Beck Depression Inventory®-II (BDI®-II). Accessed March 3, 2011 at: <http://pearsonassess.com>.
17. Hamilton M. A rating scale for depression. *J Neurol Neurosurg Psychiatry*. 1960;23:56-62.
18. Cella DF, Dineen K, Arnason B, et al. Validation of the Functional Assessment of Multiple Sclerosis Quality of Life Instrument. *Neurology*. 2006;47:29-39.

19. Hobart JC, Riazi A, Lamping DL, et al. Improving the evaluation of therapeutic interventions in multiple sclerosis: Development of a patient-based measure of outcome. *Health Technol Assess*. 2004;8:1-48.
20. Lawton MP, Brody EM. Assessment of older people: self maintaining and instrumental activities of daily living. *Gerontologist*. 1969;9:179-186.
21. Nortvedt MW, Riise T. The use of quality of life measures in multiple sclerosis research. *Mult Scler*. 2003;9:63-72.
22. Miller DM, Allen R. Quality of life in multiple sclerosis: determinants, measurement, and use in clinical practice. *Curr Neurol Neurosci Rep*. 2010;10:397-406.
23. Kern S, Schrempf W, Schneider H, et al. Neurological disability, psychological distress, and health-related quality of life in MS patients within the first three years after diagnosis. *Mult Scler*. 2009;15:752-758.
24. Goldman Consensus Group. The Goldman consensus statement on depression in multiple sclerosis. *Mult Scler*. 2005;11:328-337.
25. Siegert RJ, Abernathy DA. Depression in multiple sclerosis: A review. *J Neurol Neurosurg Psychiatry*. 2005;76:469-475.
26. Kurt A, Nijboer F, Matuz T, et al. Depression and anxiety in individuals with amyotrophic lateral sclerosis: Epidemiology and management. *CNS Drugs*. 2007;21:279-291.
27. Jaracz K, Pawlak M, Górna K, et al. Quality of life and social support in patients with multiple sclerosis. *Neurol Neurochir Pol*. 2010;44:358-365.
28. Amato MP, Zipoli V, Portaccio E. Multiple sclerosis-related cognitive changes: a review of cross-sectional and longitudinal studies. *J Neurol Sci*. 2006;245:41-46.
29. Mitchell A, Kemp S, Benito-Leon J, et al. The influence of cognitive impairment on health-related quality of life in neurological disease. *Acta Neuropsychiatrica*. 2010;22:2-13.
30. Baumstarck-Barrau K, Simeoni MC, Reuter F, et al. Cognitive function and quality of life in multiple sclerosis patients: A cross-sectional study. *BMC Neurol*. 2011;11:17.
31. Benito-Leon J, Morales JM, Rivera-Navarro J. Health-related quality of life and its relationship to cognitive and emotional functioning in multiple sclerosis patients. *Eur J Neurol*. 2002;9:497-502.
32. Hadjimichael O, Vollmer T, Oleen-Burkey M. Fatigue characteristics in multiple sclerosis: the North American Research Committee on Multiple Sclerosis (NARCOMS) survey. *Health Qual Life Outcomes*. 2008;6:100.
33. Costello K, Harris C. Differential diagnosis and management of fatigue in multiple sclerosis: Considerations for the nurse. *J Neurosci Nurs*. 2003;35:139-148.
34. White CP, White MB, Russell CS. Invisible and visible symptoms of multiple sclerosis: Which are more predictive of health distress? *J Neurosci Nurs*. 2008;40:85-95.
35. Schwartz CE, Coulthard-Morris L, Zeng Q. Psychosocial correlates of fatigue in multiple sclerosis. *Arch Phys Med Rehabil*. 1996;77:165-70.
36. Thomas PW, Thomas S, Kersten P, et al. Multicentre parallel-arm randomised controlled trial to assess the effectiveness and cost-effectiveness of a group-based cognitive behavioural approach to managing fatigue in people with multiple sclerosis. *BMC Neurology*. 2010;10:43.
37. Morin C, Bushnell MC, Lusk MB, et al. Disruption of thermal perception in a multiple sclerosis patient with central pain. *Clin J Pain*. 2002;18:191-195.
38. Newland PK, Naismith RT, Ullione M. The impact of pain and other symptoms on quality of life in women with relapsing-remitting multiple sclerosis. *J Neurosci Nurs*. 2009;41:322-328.
39. Reyes-Gibby CC, Mendoza TR, Wang S, et al. Pain and fatigue in community dwelling adults. *Pain Med*. 2003;4:231-237.
40. O'Leary SA, Phillips JT. Optimizing quality of life in multiple sclerosis. *Medscape Neurol Neurosurg*. June 21, 2007. Accessed March 3, 2011 at: www.medscape.org/viewarticle/558261.
41. Jongen PJ, Lehnick D, Sanders E, et al; FOCUS study group. Health-related quality of life in relapsing remitting multiple sclerosis patients during treatment with glatiramer acetate: A prospective, observational, international, multi-centre study. *Health Qual Life Outcomes*. 2010;15:8:133.
42. Lily O, McFadden E, Hensor E, et al. Disease-specific quality of life in multiple sclerosis: The effect of disease modifying treatment. *Mult Scler*. 2006;12:808-813.
43. Jongen PJ, Sindic C, Carton H, et al. Functional composite and quality of life in Avonex-treated Relapsing multiple sclerosis patients (FLAIR) study group: Improvement of health related quality of life in relapsing remitting multiple sclerosis patients after 2 years of treatment with intramuscular interferon-beta-1a. *J Neurol*. 2010;257:584-589.
44. Rudick RA, Miller D, Hass S, et al; AFFIRM and SENTINEL Investigators. Health-related quality of life in multiple sclerosis: Effects of natalizumab. *Ann Neurol*. 2007;62:335-346.
45. Motl RW, McAuley E, Snook EM, et al. Physical activity and quality of life in multiple sclerosis: Intermediary roles of disability, fatigue, mood, pain, self-efficacy and social support. *Psychol Health Med*. 2009;14:111-124.
46. Grossman P, Kappos L, Gensicke H, et al. MS quality of life, depression, and fatigue improve after mindfulness training. *Neurology*. 2010;75:1141-1149.

CP Counseling Points™

Preserving Quality of Life in MS

- Quality of life (QOL) must be individualized for each patient and encompass the physical, social, psychological, and spiritual dimensions of a person's well-being.
- Strong predictors of poor QOL in multiple sclerosis (MS) include cognitive impairment, depression, lack of autonomy or support, and chronic pain. Moderate predictors include fatigue, anxiety, communication problems, and bladder/sexual dysfunction.
- QOL does not correlate well with physical measures of disease such as the Expanded Disability Status Scale (EDSS) and does not decrease in a linear fashion as disease severity worsens.
- Widely used research instruments for measuring QOL in MS (such as the MSQOL-54) often are not used in a clinical setting due to time constraints. However, these assessments can provide valuable insight into patient perceptions of QOL.
- MS symptoms that reduce QOL—such as fatigue, pain, depression, and sleep disturbance—tend to be interrelated. For example, pain can increase sleep disturbance, which can exacerbate fatigue.
- Many current research studies of MS disease-modifying therapies are acknowledging QOL as an important goal of treatment. Studies of agents such as glatiramer acetate and natalizumab, and nonpharmacologic approaches such as exercise, have demonstrated that QOL can be improved with treatment.
- Communicating with patients about QOL involves viewing MS within the “big picture,” accounting for changing life circumstances, listening with empathy, promoting self-efficacy, and helping patients to establish realistic treatment goals.

Counseling Points™

Preserving Quality of Life in MS

Continuing Education Posttest

To receive contact hours, please read the program in its entirety, answer the following posttest questions, and complete the program evaluation. A certificate will be awarded for a score of 80% (8 correct) or better. A certificate will be mailed within 4 to 6 weeks. There is no charge for the CNE credit.

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Via the Web: Applicants can access this program at the International Organization of MS Nurses' website, www.IOMSN.org. Click on Counseling Points and follow the instructions to complete the online posttest and application forms.

PLEASE SELECT THE BEST ANSWER

- In a study by Mitchell, strong predictors of poor quality of life (QOL) in multiple sclerosis (MS) included all of the following EXCEPT:**
 - cognitive impairment
 - lack of autonomy and support
 - higher Expanded Disability Status Scale score
 - chronic pain
- In the same study as above, moderate predictors included all of the following EXCEPT:**
 - fatigue
 - anxiety
 - low self-esteem
 - male sex
- QOL in MS usually decreases in a linear manner as the number of symptoms and degree of disability increase.**
 - True
 - False
- Which of the following acronyms does NOT represent a standardized instrument for evaluating QOL in MS?**
 - NMSS-QOL
 - MSQOL-54
 - MSQLI
 - FAMS
- Symptoms shown to have a significant impact on QOL in people with MS include:**
 - fatigue
 - depression
 - pain
 - all of the above
- Depression in MS has been shown primarily to affect:**
 - people with longstanding disease
 - people with a prior history of psychiatric diseases
 - people with other medical comorbidities
 - people at all stages of the disease
- The most common symptom of MS, affecting up to 75% of patients, is:**
 - depression
 - fatigue
 - bladder dysfunction
 - cognitive dysfunction
- The vicious cycle of MS symptoms occurs because:**
 - many symptoms share the same neuropathways
 - the impact of MS symptoms on a person's life is cumulative and interrelated
 - worry, depression, and anxiety can worsen symptoms
 - all of the above
- Studies of disease-modifying therapies such as glatiramer acetate, beta interferon, and natalizumab show that treatments can improve physical parameters but not QOL measures.**
 - True
 - False
- In a study by Motl on the impact of exercise in MS, the authors found that exercise increases QOL by:**
 - increasing endorphin levels in the bloodstream
 - reducing cortisol levels in the bloodstream
 - reducing depression, fatigue, and physical disability
 - none of the above
- Self-efficacy is defined as a person's feeling that he or she:**
 - can make a difference in the world
 - can compete against others in the work environment
 - has control over a difficult situation
 - can take care of all activities of daily living
- Helping patients set realistic treatment goals involves all of the following EXCEPT:**
 - eliminating all goals deemed unrealistic
 - adjusting goals as circumstances change
 - defining and celebrating short-term, realistic goals
 - individualizing goals according to the patient's own QOL definition

Counseling Points™: Program Evaluation Form

Preserving Quality of Life in MS

Using the scale provided, Strongly Agree = 5 and Strongly Disagree = 1, please complete the program evaluation so that we may continue to provide you with high quality educational programming. Please fax this form to **(201) 612-8282**.

5 = Strongly Agree 4 = Agree 3 = Neutral 2 = Disagree 1 = Strongly Disagree

At the end of this program, I was able to: *(Please circle the appropriate number on the scale.)*

- 1. Review findings of recent research on multiple sclerosis (MS) quality of life (QOL)..... 5 4 3 2 1
- 2. Discuss how symptoms of MS such as depression, cognitive dysfunction, and fatigue can impact QOL..... 5 4 3 2 1
- 3. Evaluate MS-specific instruments for measuring QOL..... 5 4 3 2 1
- 4. Initiate discussion about QOL with patients and monitor changes over the course of the disease..... 5 4 3 2 1

To what extent was the content:

- 5. Well-organized and clearly presented 5 4 3 2 1
- 6. Current and relevant to your area of professional interest 5 4 3 2 1
- 7. Free of commercial bias..... 5 4 3 2 1
- 8. Clear in providing disclosure information 5 4 3 2 1

General Comments

9. As a result of this continuing education activity (check only one):

- I will modify my practice. (If you checked this box, how do you plan to modify your practice?) _____
- I will wait for more information before modifying my practice.
- The program reinforces my current practice.

Suggestions for future topics/additional comments: _____

Follow-up

As part of our continuous quality-improvement effort, we conduct postactivity follow-up surveys to assess the impact of our educational interventions on professional practice. Please check one:

- Yes, I would be interested in participating in a follow-up survey.
- No, I would not be interested in participating in a follow-up survey.

There is no fee for this educational activity.

Posttest Answer Key	1	2	3	4	5	6	7	8	9	10	11	12

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