

Now Offering
Complimentary Continuing
Education Credit for Nurses

Fall 2012
Volume 8, Number 3

Counseling Points™

Enhancing Patient Communication for the MS Nurse



Treating the Whole Patient: Applying Comprehensive Care in MS

Series Editor

Amy Perrin Ross, APN, MSN, CNRN, MSCN

Faculty Panel

June Halper, MSN, RN, CS, ANP

Patricia Kennedy, RN, CNP, MSCN

Tracy Walker, FNP-C, WOCN, MSCN

This continuing education publication is supported by an educational grant from Teva CNS.

FACULTY:

Series Editor

Amy Perrin Ross, APN, MSN, CNRN, MSCN
Neuroscience Program Coordinator
Loyola University Medical Center
Maywood, IL

Faculty Panel

June Halper, MSN, APN-C, MSCN
Executive Director
Consortium of Multiple Sclerosis Centers
Hackensack, NJ

Patricia Kennedy, BSN, RN, CNP, MSCN
Nurse Educator
Programs Consultant
Can Do Multiple Sclerosis
Edwards, CO

Tracy Walker, FNP-C, WOCN, MSCN
Nurse Practitioner
The Andrew C. Carlos MS Institute at Shepherd
Shepherd Center
Atlanta, GA

Planning Committee

All faculty served as members of the planning committee.

Faculty Disclosure Statements

Amy Perrin Ross has received honoraria for consulting and participating on the Speakers' Bureaus for Bayer HealthCare, Inc., EMD Serono, Novartis, Pfizer, Inc, and Teva Neuroscience.

June Halper serves as a consultant and a non-CME speaker for Acorda Therapeutics.

Pat Kennedy has received honoraria for consulting for Acorda Therapeutics, Biogen Idec, EMD Serono, Genzyme, Novartis, and Teva Neuroscience.

Tracy Walker has received honoraria for serving as a consultant and speaker for Acorda Pharmaceuticals, Biogen Idec, EMD Serono/Pfizer, Novartis, Questcor, and Teva Neuroscience.

Laurie Scudder, DNP, NP, served as the reviewer and nurse planner for this activity and has disclosed no relevant financial relationships.

Planners and Managers

The following planners and managers have declared no relevant financial relationships: Joseph J. D'Onofrio, Frank Marino, Nancy Monson, Katherine Wandersee.

PUBLISHING INFORMATION:

Publishers

Joseph J. D'Onofrio
Frank M. Marino
Delaware Media Group
66 South Maple Avenue
Ridgewood, NJ 07450
Tel: 201-612-7676
Fax: 201-612-8282
Websites: www.delmedgroup.com
www.counselingpoints.com

Editorial Director

Nancy Monson

Medical Writer

Katherine Wandersee

Art Director

James Ticchio

Cover photo credit: © ImageZoo Illustration / Veer

Copyright © 2012, Delaware Media Group, Inc. All rights reserved. None of the contents may be reproduced in any form without prior written permission from the publisher. The opinions expressed in this publication are those of the faculty and do not necessarily reflect the opinions or recommendations of their affiliated institutions, the publisher, or Teva CNS.

Counseling Points™

Treating the Whole Patient:

Applying Comprehensive Care 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 provide MS nurses with information and tools to apply comprehensive care principles to people with MS.

Learning Objectives

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

- Review the rationale for multidisciplinary management in MS and describe the principles of integrated care
- Analyze the interrelationship between MS symptomatology and overall health
- Describe approaches for integrating nursing assessment, treating symptoms, and management of health and wellness in MS

Continuing Education Credit

This continuing nursing education activity is coprovided by Delaware Media Group and NP Alternatives.

NP Alternatives is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

Laurie Scudder, DNP, NP, served as nurse planner for this activity. She has declared no relevant financial relationships.

This activity has been awarded 1.0 contact hours (0.0 contact hours are in the area of pharmacology). Code: MSCP0912.

In order to earn credit, please read the entire activity and complete the posttest and evaluation at the end. Approximate time to complete this activity is 60 minutes.

This program expires November 30, 2014.

Disclosure of Non-endorsement of Products

Accreditation does not imply endorsement by NP Alternatives or the American Nurses Credentialing Center's Commission on Accreditation of the educational activity or any commercial products discussed in conjunction with an educational activity.

Disclosure of Unlabeled Use

This educational activity may contain discussion of published and/or investigational uses of agents that are not approved by the FDA. Teva CNS and Delaware Media Group do not recommend the use of any agent outside of the labeled indications. The opinions expressed in the educational activity are those of the faculty and do not necessarily represent the views of Teva CNS and Delaware Media Group.

Disclaimer

Participants have an implied responsibility to use the newly acquired information to enhance patient outcomes and their own professional development. The information presented in this activity is not meant to serve as a guideline for patient management. Any medications, diagnostic procedures, or treatments discussed in this publication should not be used by clinicians or other health care professionals without first evaluating their patients' conditions, considering possible contraindications or risks, reviewing any applicable manufacturer's product information, and comparing any therapeutic approach with the recommendations of other authorities.

welcome

Dear Colleague,

Over 25 years ago, the Consortium of Multiple Sclerosis Centers (CMSC) was formed around the idea that multiple sclerosis (MS) management should involve comprehensive care of the whole person. During the quarter-century since, healthcare delivery has become increasingly specialized, and sometimes fragmented. Patient care is often delivered in “silos” specific to the disease state, with few centralized sources to assess how one medical condition might be affecting another. In the field of MS care, have we succeeded with this comprehensive care model proposed years ago?

Comprehensive, whole-person care is the goal of many specialized MS centers, but these principles also can be applied in an office or clinic that provides care for people with MS. How is comprehensive care of the “whole person” being addressed in your center or clinic, and how can it be improved? Is the MS care provider the “medical home,” or does the patient receive basic medical care from a primary care provider? If so, is communication between the MS care provider and the primary care provider sufficient to deliver the best care to the patient and prevent any potential drug-drug interactions or incompatible medical procedures?

These concepts are the focus of this issue of *Counseling Points*[™]. We explore how comorbidities and other individual patient characteristics affect comprehensive MS care. Other challenges include today’s managed-care-oriented system, where cost-control measures are sometimes the overriding decision makers.



Amy Perrin Ross, APN, MSN, CNRN, MSCN (series editor)
Neuroscience Program Coordinator
Loyola University Medical Center
Maywood, IL

Treating the Whole Patient: Applying Comprehensive Care in MS

Multiple sclerosis (MS) is not, and never will be, a “one size fits all” condition. Optimal care of a person with MS requires an individualized, patient-centered approach that:

1. recognizes and treats multiple aspects of the person’s health;
2. addresses symptoms, systemic effects of the disease, and comorbidities;
3. adapts to the necessary changes throughout the person’s lifetime; and
4. encourages collaboration and communication among the healthcare team members and across healthcare sectors.

Comprehensive care—also called integrated care—is not a new idea in MS. While most healthcare providers support the idea of comprehensive, whole-person care in theory, there are several important barriers inherent in today’s healthcare delivery system that may interfere with a comprehensive approach to care. These include lack of reimbursement, lack of adequate time to spend with patients, and lack of communication between providers.^{1,2}

MS nurse specialists and other nurses who care for people with MS are often in a position to provide and make decisions about comprehensive care. This may involve treating patients with MS for health conditions that might normally be considered primary care, or ensuring that a patient is referred for and follows through with non-MS-related health visits such as mammography. By having a more complete understanding of the goals and objectives of comprehensive care in MS,

nurses can determine whether changes are warranted in care delivery or overall philosophy to promote greater wellness and well-being for the person with MS.

Rationale for Comprehensive/Integrated Care in MS

One of the founding principles of the Consortium of Multiple Sclerosis Centers (CMSC) is to promote comprehensive care in MS. To manage MS effectively, disease modification must be addressed along with physical symptoms and the psychological, social, economic, lifestyle, and quality of life (QOL) aspects of health.³ In 2011, the CMSC issued a special supplement, *Best Practices in Comprehensive MS Symptomatic Management*, based on a CMSC consensus conference.⁴ The multidisciplinary consensus team compiled a statement of best practices for comprehensive symptom management in MS, which is reprinted in **Table 1**.³

Definitions of Comprehensive and Integrated Care

The concepts of comprehensive care and integrated care often overlap. The goal of comprehensive care is to focus on the whole person, while the main goal of integrated care is to foster communication among members of the healthcare team.⁵ In the chronic care model, integrated care is defined as “a continuum of patient-centered services for persons with chronic conditions, with the goal of achieving optimal daily functioning and health status for the individual and achieving and maintaining the individual’s independence and functioning in the community.”²

Table 1. CMSC Statement of Best Practices: Comprehensive MS Symptomatic Management³

- Everyone affected by MS—including patients and their families—could benefit from “comprehensive care,” which should include education, baseline measurement of physical, cognitive and psychosocial status, comprehensive assessment, and treatment of symptomatic issues, as appropriate over the disease trajectory. To achieve full benefit, the person with MS must be willing to participate and the payer must also realize that comprehensive care costs may initially be higher than the cost of traditional care. However, the long-term goal is to minimize suffering and the unpredictable changes associated with MS, maximize patient function, and to reduce overall healthcare costs associated with secondary complications, use of hazardous or expensive treatments, and overlapping of services.
- The components of comprehensive care include establishing care, continuing care, and sustaining care in a coordinated fashion. The goal is to provide rational services as needed; not every person needs every service every time. Comprehensive care is not a “one time” assessment, but a series of ongoing evaluations and treatments over the life of the person with MS by the appropriate members of the MS care team.
- General principles of comprehensive care in MS:
 - Patient goals frame comprehensive care
 - Appropriate services provided through comprehensive care providers are ultimately cost effective
 - Comprehensive care should not replace patient/family wishes
 - Access to comprehensive care is possible for all patients with MS
 - Comprehensive care includes medical, rehabilitation, social, and vocational matters that impact or are impacted by the patient’s health status

CMSC=Consortium of Multiple Sclerosis Centers; MS=multiple sclerosis.

Reprinted with permission from Halper J. Comprehensive care in multiple sclerosis – best practices. *Int J MS Care*. 2011;13(Suppl 4):33-36.³

The World Health Organization (WHO) defines integrated care as “a concept bringing together inputs, delivery, management, and organization of services related to diagnosis, treatment, care, rehabilitation, and health promotion.”⁶ Other definitions stress the needs of the individual patient, describing integrated care as “an organizational process of coordination that seeks to achieve seamless and continuous care, tailored to the patient’s needs, and based on a holistic view of the patient.”⁷

Role of Comprehensive/Integrated Care in MS Care Delivery

There are many aspects of managing MS that make a comprehensive care approach particularly well suited.

Adjusting Focus of Care Over Lifetime of Disease

In a person with a lifelong condition such as MS, providers must adapt the approach to care as the needs of the individual change over time.⁸ MS is a progressive disease with many systemic manifestations and comorbidities, which result in loss of function, need for high-cost treatments, high demand for both scheduled and unscheduled medical care, and increased risks of morbidity and mortality.³ The short-term goals of managing MS are to stabilize function, to avoid or delay further deterioration, and to minimize comorbidities or complications that may occur during the disease course.⁹ The overriding goals are to sustain independence, assist the patient in making educated decisions, and engage in realistic planning over the long course of the disease.³ This care plan must be reevaluated as the needs of the person with MS change over time.

Managing MS Symptoms Affecting Multiple Body Systems

Disease management in MS includes effective disease modification, along with treatment of

relapses, managing symptoms, and assisting in the necessary psychosocial and lifestyle adjustments. The unpredictable nature of MS demands treatments and interventions to manage various MS symptoms, which may include any combination of weakness, fatigue, cognitive impairment, impaired gait and balance, visual deficits, spasticity, pain, bladder/bowel dysfunction, and sexual dysfunction. Having to cope with and manage multiple symptoms can seem overwhelming to an individual, family members, and sometimes healthcare providers.³ With a comprehensive care approach, these needs are addressed and followed through by an interdisciplinary team of specialized providers, in conjunction with a primary care provider.¹⁰

Initiating and Maintaining Communication Among Team Members

Care for a person with MS may involve services provided by neurologists and nurses; psychologists; medical specialists such as ophthalmologists and urologists; physical, occupational, and speech therapists; and primary care providers.¹¹ In an ideal environment, MS clinicians are able to share records, lab results, and other patient information.

Communication among care providers helps the patient to recognize that his/her needs are being addressed and helps to avoid duplication and/or fragmentation of services. Improving communication among providers also has been shown to reduce hospitalizations, service duplication, and emergency room visits.¹²

Communication must include the patient, family members, and caregivers, who are integral partners on the healthcare team. The person with MS is encouraged to actively participate in care planning, and is expected to take responsibility and accountability for carrying out some degree of self-care and adherence to the selected treatment approaches.¹³

Studies suggest that fragmentation of healthcare negatively affects MS care delivery.⁵ In a review of integrated care in MS, Wallin observed “Like other chronic conditions, coordination and continuity of care for patients with MS are often suboptimal.”¹¹ This author cites several studies identifying significant unmet needs in people with MS due to discontinuity and fragmentation of the healthcare delivery system.^{14,15}

Cost Containment

Although comprehensive care may be accepted as the best practice for patients with MS, receiving reimbursement for comprehensive care may be difficult within the current system.⁵ For the most part, the system does not encourage communication between providers or team approaches to care of chronic diseases.¹¹ Instead, specialized medical practices tend to function as individual “silos,” with limited incentive for communicating with other providers caring for the patient.¹¹

Studies in MS and other conditions have demonstrated economic benefits to comprehensive care when viewed on a long-term basis. Comprehensive care can reduce overall healthcare costs by yielding improved outcomes, reducing the burden of disease, and fostering better quality of life.^{16,17} Thrower has pointed out that of the \$2.1 trillion spent on healthcare in the United States in 2008, 95% was for management of chronic illness and only 5% was spent on disease prevention.⁵

Where Is MS Care Being Delivered?

The membership of the CMSC includes more than 200 specialized MS centers in the United States, Canada, and Europe, which provide care for more than 150,000 people with MS.¹⁸ However, in a survey commissioned by the National Multiple Sclerosis Society, only 38% of people with MS responding said they received their care

from a specialist in MS; most of the remaining patients received care from general neurologists, neurology clinics, or in primary care settings.⁵

One of the problems with a fragmented system of care for chronic conditions such as MS is that it requires the patient to navigate a confusing and often-frustrating medical system without knowing who's in charge or how to coordinate the bewildering array of tests, appointments, and treatment protocols.¹⁹ Ideally, the patient makes decisions, backed by a support team in which all members are on the "same page." This principle is encompassed in the patient-centered medical home, or PCMH.^{11,20} This model attempts to coordinate primary care and specialty care with an advanced electronic medical record serving as a communication vehicle between healthcare providers and the patient (**Table 2**).^{21,22} The electronic system should include decision support tools to help cre-

Table 2. Five Pillars of PCMH Model²¹

According to the Agency for Healthcare Research and Quality, a PCMH model rests on five pillars:

1. A patient-centered orientation, which focuses on each person's needs, culture, values, and preferences. This orientation supports the patient's self-care efforts and involves the patient in care plans.
2. Comprehensive, team-based care, which meets the majority of the patient's physical and mental health needs, including prevention and wellness, acute care, and chronic care.
3. Coordination across all elements of the healthcare system that is connected to the patient.
4. Access to care that meets the patient's needs and preferences, including email and telephone contact after hours.
5. A systems-based approach to quality and safety that includes gathering and responding to patient data and a commitment to quality improvement.

PCMH=Patient-centered medical home.

ate an individualized care plan for the patient and engage the patient to be involved with care. These tools may include targeted patient and caregiver education, rehabilitation programs the patient can view electronically, webcam "visits" with the patient, and tools to improve adherence.²² Some questions about the feasibility of PCMH are the difficulty of receiving adequate reimbursement and the challenges to small practices for adopting the model.²¹ More information about how to apply PCMH principles in primary care practices can be obtained from the Patient Centered Primary Care Collaborative (www.pcpcc.net).

Self-Management Principles in MS

Self-management is an aspect of MS essential to successful integrated care. Self-management has three main components:

1. patient and family/caregiver education;
2. behavioral support; and
3. motivational support.²³

The primary objective of self-management is to promote behavioral changes that contribute to how patients manage their condition.^{23,24} **Table 3** outlines some of the steps that can be applied to promote behavioral change for effective self-management.

One of the steps in self-management is to promote patient self-efficacy in decision making.

Table 3. Steps to Promote Behavioral Change in Self-Management of MS²⁴

1. Formulate treatment goals that are relevant to the patient
2. Encourage patients to experiment with adaptive behaviors in everyday situations
3. Encourage problem solving and decision making
4. Promote self-efficacy in care delivery and decisions

“Self-efficacy” is defined as “the belief that one can successfully execute particular behaviors to produce certain outcomes, and is a major determinant for inducing and maintaining these behaviors.”²⁴ Ongoing assessment of patient self-efficacy is critical to the success of chronic disease management. Higher levels of self-efficacy have been shown to lead to positive health behaviors, such as improved adherence with prescribed therapies and treatment approaches, regular exercise, and stress and fatigue management.^{22,25}

Focus on Patient Well-being in MS

Management approaches that focus primarily on controlling disease progression and minimizing disability measures often do not take patient well-being into account. While well-being is a somewhat broad concept, in many MS care centers increasing priority is placed on supporting overall wellness coupled with a positive approach to managing the disease. This may involve encouraging the person with MS to participate in activities that help to improve and maintain optimal levels of well-being. Some of these strategies may include exercise, stress management, optimal nutrition, positive social interactions and social support, and responsible health practices.²⁶ While these steps may seem obvious, people with MS (and often those without MS as well) may express difficulty undertaking these activities or even knowing where to start.²⁷ Fear of fatigue or worsening symptoms may discourage people with MS from exercising. Others may feel overwhelmed by the notion that they should be exercising more than they are, or feel pressure to participate in high-level activities such as biking or running. In these cases, a program should be designed to meet individual needs, with a combination of exercise and daily activities that account for fluctuations in MS symptoms such as fatigue.

Managing stress is another aspect of well-being that is essential for people with MS. In addition to the normal stresses of life that trigger or amplify physical symptoms such as headaches, digestive disorders, and fatigue, there is the added stress of living with MS. Recent studies have suggested that stress may have an impact on disease progression. A study by Rapaport compared magnetic resonance imaging (MRI) findings among 60 people with MS who received stress management therapy (16 therapy sessions over 20 to 24 weeks) with those of 61 people who did not receive the therapy (the “waitlist” group).²⁸ A greater proportion of the therapy group remained free of new lesions during the study period compared with the waitlist group. Because stress management strategies are a key part of comprehensive care in MS, patients should be offered services or referrals to programs individualized for their needs.²⁸ The MS nurse can serve as an advocate to assist patients in receiving the treatment or programs needed to manage this aspect of their condition.

An interesting and encouraging direction for MS care in the past few decades has been the introduction of care models that focus more on patient well-being and positive approaches to wellness for those with MS. One notable example is Can Do Multiple Sclerosis, formerly the Heuga Center for MS, in Edwards, Colorado. The philosophy of Can Do MS is to focus on what the person *can* do, and not on the limitations imposed by the disease. Exercise, education, nutrition, physical therapy, and emotional well-being are important components of this model. This educational organization offers life empowerment programs for people with MS in the United States and Canada. These programs are highlighted in a recent book for people with MS, *The Can Do Multiple Sclerosis Guide to Lifestyle Empowerment*,

edited by Patricia Kennedy and available via online booksellers and in bookstores.

Optimizing QOL in MS

Enhancing QOL is an important goal of comprehensive MS care. QOL is defined as “a subjective measure of a patient’s life satisfaction that is affected by mood, coping mechanisms, life experiences, and emotional support as well as disease state.”²⁹ MS has been shown to impact QOL by interfering with a person’s ability to work, pursue leisure activities, and carry out life roles.³⁰ Study results have indicated that people with MS have lower scores in QOL assessments than those with other types of disabilities.³¹ Certain MS symptoms and disease characteristics have been shown to be predictors of poor QOL, as shown in **Table 4**.³² To aid in communicating with patients about QOL, it may be helpful for MS clinicians to utilize validated assessment tools (**Table 5**).

In planning for care, it is important to incorporate plans for emotional support and promoting self-efficacy, in addition to focusing on skills such as balance and gait improvement.²⁹ Interestingly, while clinicians may assume that physical limitations are the predominant concerns of people with MS, some studies have suggested that patients tend to rank limitations in mental health and emotional roles and social activities as being of greater priority for QOL.²⁹ Healthcare providers may believe that administering a QOL screening instrument takes too much time given the other demands of caring for someone with MS. However, the findings from these assessments can help guide decisions about treatment, adherence, physical activity, safety in the home, the patient’s emotional status, and many other aspects of MS care.

As its importance is recognized, QOL is now one of the outcomes measured in clinical trials of disease-modifying therapies (DMTs) for

Table 4. Predictors of Poor QOL in MS³³

Strong Predictors

- Cognitive impairment
- Depression, demoralization
- Lack of autonomy
- Lack of social 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

QOL=quality of life.

MS. In addition, studies are emerging showing that patients treated with DMTs have improved QOL over nontreated patients. A study on the effect of glatiramer acetate on MS QOL by Jongen and colleagues compared 91 patients with relapsing-remitting MS with prior exposure to immunomodulatory drugs and 106 treatment-naïve patients.³³ 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 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.³³ In a study of intra-

Table 5. QOL Assessment Tools for MS

- Multiple Sclerosis Quality of Life-54 (MSQOL-54)
- Multiple Sclerosis Quality of Life Inventory (MSQLI)
- Beck Depression Inventory
- Multiple Sclerosis Modified Fatigue Impact Scale
- Short Form SF-36

Instructions, overviews, and links to these instruments are available from the National Multiple Sclerosis Society's website (www.nationalMSSociety.org), For Professionals, Clinical Study Measures.

MS=multiple sclerosis; QOL=quality of life.

muscular interferon beta-1b, the same authors found that treatment for 2 years was associated with increased QOL, especially among younger people with lower levels of disability.³⁴ Patients who discontinued the active treatment were found to have lower physical and mental HR-QoL at baseline.³⁴

Managing Comorbidities in MS

People with MS, caregivers, and even healthcare providers may overlook the fact that MS does not occur in isolation. Other health conditions affecting the general population can just as easily—or in some cases more frequently—afflict those with MS. In recent years, greater recognition has been given to the influence of comorbid medical conditions on MS. While there is a growing body of research on this topic, according to Marrie and colleagues, medical comorbidities represent a “crucial gap in knowledge” for patients and clinicians (**Table 6**).³⁵

“Comorbidity” refers to the total burden of illness other than the specific disease of interest, and is distinct from complications of the disease such as fatigue or spasticity.³⁵ Comorbidities may occur by chance, through common etiological mechanisms such as heredity, or via related risk factors

Table 6. Prevalence of Comorbid Medical Conditions Among People With MS³⁵

Hyperlipidemia	37%
Hypertension	30%
Arthritis	16%
Irritable bowel syndrome	13%
Chronic lung disease	13%
Restless legs syndrome	13% to 37%
Depression	50% (nearly 3 times higher than general population)

Based on 2006 NARCOMS registry comorbidity report from 8,983 participants.

(such as smoking). In some cases there is direct causation, in which one disorder leads directly to another. For example, some cases of mental or psychological illness may be caused by alterations in brain chemistry due to MS.³⁶ Common risk factors can lead to increased co-occurrence of disease. An example of this would be the common genetic susceptibility believed to underlie the increased incidence of other autoimmune disorders in people with MS.³⁷ Other independent factors such as age, obesity, and poor diet can be associated with increased co-occurrence of disease (heterogeneity).³⁵

Comorbidities have been associated with increased progression of disability in people with MS. For example, vascular comorbidities such as diabetes, hypertension, dyslipidemia, heart disease, and peripheral vascular disease, are associated with more rapid progression of ambulatory disability than when these comorbidities are absent.³⁸ In another study that observed patients newly diagnosed with MS over a 3-year period, people with musculoskeletal comorbidities had greater declines

in physical functioning than those without such comorbidities.³⁹

Comorbid health conditions can have an important influence on the choice of DMTs and other medications used to treat MS symptoms. For example, the presence of liver disease may be a contraindication for the use of interferon beta and some of the newer MS drugs, while cardiovascular complications may present a contraindication for use of fingolimod. There are limited data on the safety of using MS drugs concomitantly with other medications, in part because people with comorbidities are typically excluded from MS clinical trials.³⁵ In addition, comorbidities may reduce adherence to therapy because of depression, cognitive dysfunction, and the demands of taking multiple medications throughout the day for multiple conditions.⁴⁰

Conclusion

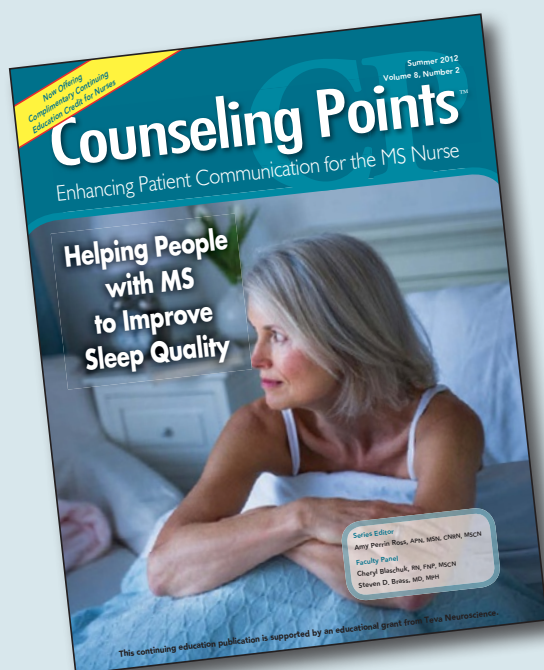
While much of the attention in MS today is focusing on improvements in DMTs, this is only one aspect of a complex health condition that is best managed using a comprehensive, whole-patient approach. Regardless of the type of practice setting, MS care practitioners must look for ways to enhance communication between providers and with the patient, consider important factors such as QOL and patient self-efficacy, and manage primary care needs and comorbidities in addition to MS symptoms.

References

1. Pozniak A, Olinger L, Shier V. Physicians' perceptions of reimbursement as a barrier to comprehensive diabetes care. *Am Health Drug Benefits*. 2010;3(1):31-40.
2. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the chronic care model, Part 2. *JAMA*. 2002;288(15):1909-1914.
3. Halper J, Schapiro R. Comprehensive care in multiple sclerosis – best practices. *Int J MS Care*. 2011;13(Suppl 4):33-36.
4. Best Practices in Comprehensive MS Symptomatic Management: Reports from a CMSC Consensus Conference. *Int J MS Care*. June 2011;13(Suppl 4). Available at: <http://ijmsc.org>.
5. Thrower B. Comprehensive care in multiple sclerosis. *Int J MS Care*. 2011;13(Suppl 4):1-7.
6. World Health Organization. The World Health Report 1998. Life in the 21st century: a vision of all. Geneva: WHO, 1998.
7. Mur-Veeman I, Hardy B, Steenbergen M, et al. Development of integrated care in England and the Netherlands: managing across public-private boundaries. *Health Policy*. 2003;65(3):227-241.
8. Corbin JM. The Corbin and Strauss Chronic Illness Trajectory model: an update. *Sch Inq Nurs Pract*. 1998;12(1):33-41.
9. Norris SL, Glasgow RE, Engelgau MM, et al. Chronic disease management: A definition and systematic approach to component interventions. *Dis Manage & Health Outcomes*. 2003;11(8):477-488.
10. Burks JS, Johnson KP. *Multiple Sclerosis: Diagnosis, Medical Management, and Rehabilitation*. New York: Demos; 2000.
11. Wallin MT. Integrated multiple sclerosis care: new approaches and paradigm shifts. *J Rehabil Res Dev*. 2010;47(5):ix-xiv.
12. Fisher ES. Building a medical neighborhood for the medical home. *N Engl J Med*. 2008;359(12):1202-1205.
13. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med*. 2003;26(1):1-7.
14. Makepeace RW, Barnes MP, Semlyen JK, et al. The establishment of a community multiple sclerosis team. *Int J Rehabil Res*. 2001;24(2):137-141.
15. Pozzilli C, Brunetti M, Amicosante AM, et al. Home based management in multiple sclerosis: results of a randomised controlled trial. *J Neurol Neurosurg Psychiatry*. 2002;73(3):250-255.
16. Boulton C, Green AF, Boulton LB, et al. Successful models of comprehensive care for older adults with chronic conditions: evidence for the Institute of Medicine's "retooling for an aging America" report. *J Am Geriatr Soc*. 2009;57(12):2328-2337.
17. Rotstein Z, Hazan R, Barak Y, et al. Perspectives in multiple sclerosis health care: special focus on the costs of multiple sclerosis. *Autoimmun Rev*. 2006;5(8):511-516.
18. Consortium of Multiple Sclerosis Centers. About the CMSC. Available at: <http://www.ms-care.org/cm-sc/News/About-the-CMSC.html>.
19. Jansen DE, Krol B, Groothoff JW, et al. Integrated care for MS patients. *Disabil Rehabil*. 2007;29(7):597-603.
20. Rich EC, Lipson D, Libersky J, et al. Organizing care for complex patients in the patient-centered medical home. *Ann Fam Med*. 2012;10(1):60-62.
21. Agency for Healthcare Research and Quality. The patient-centered medical home: strategies to put patients at the center of primary care. AHRQ Publication No. AHRQ 11-0029. February 2011. Available at: <http://pcmh.ahrq.gov>.
22. Miller D, Rudick RA, Hutchinson M. Patient-centered outcomes: translating clinical efficacy into benefits on health-related quality of life. *Neurology*. 2010;74 Suppl 3:S24-35.
23. Chaplin H, Hazan J, Wilson P. Self-management for people with long-term neurological conditions. *Br J Community Nurs*. 2012;17(6):250-254, 256-257.
24. Ng A, Kennedy P, Hutchinson B, et al. Self-efficacy and health status improve after a wellness program in persons with multiple sclerosis. *Disabil Rehabil*. Sep 25, 2012. Epub ahead of print.
25. Jongen PJ, Hengstman G, Hupperts R, et al. Drug adherence and multidisciplinary care in patients with multiple sclerosis: protocol of a prospective, web-based, patient-centred, nation-wide, Dutch cohort study in glatiramer acetate treated patients (CAIR study). *BMC Neurol*. 2011;11:40.
26. Stuifbergen AK, Rogers S. Health promotion: an essential component of rehabilitation for persons with chronic disabling conditions. *ANS Adv Nurs Sci*. 1997;19(4):1-20.
27. Stuifbergen AK, Roberts GJ. Health promotion practices of women with multiple sclerosis. *Arch Phys Med Rehabil*. 1997;78(12 Suppl 5):S3-9.
28. Rapaport B, Karceski S. Multiple sclerosis and stress. *Neurology*. 2012;79(5):e47-49.
29. Zwibel HL, Smrcka J. Improving quality of life in multiple sclerosis: an unmet need. *Am J Manag Care*. 2011;17(Suppl 5):S139-145.
30. Kargiotis O, Paschali A, Messinis L, et al. Quality of life in multiple sclerosis: effects of current treatment options. *Int Rev Psychiatry*. 2010;22(1):67-82.

31. 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(23):1291-1303.
32. Mitchell AJ, Benito-Leon J, Gonzalez JM, et al. Quality of life and its assessment in multiple sclerosis: integrating physical and psychological components of wellbeing. *Lancet Neurol.* 2005;4(9):556-566.
33. Jongen PJ, Lehnick D, Sanders E, et al. 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;8:133.
34. Jongen PJ, Sindic C, Carton H, et al. 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(4):584-589.
35. Marrie RA, Horwitz RI. Emerging effects of comorbidities on multiple sclerosis. *Lancet Neurol.* 2010;9(8):820-828.
36. Marrie RA, Horwitz R, Cutter G, et al. The burden of mental comorbidity in multiple sclerosis: frequent, underdiagnosed, and undertreated. *Mult Scler.* 2009;15(3):385-392.
37. Barcellos LF, Kamdar BB, Ramsay PP, et al. Clustering of autoimmune diseases in families with a high-risk for multiple sclerosis: a descriptive study. *Lancet Neurol.* 2006;5(11):924-931.
38. Marrie RA, Rudick R, Horwitz R, et al. Vascular comorbidity is associated with more rapid disability progression in multiple sclerosis. *Neurology.* 2010;74(13):1041-1047.
39. Dallmeijer AJ, Beckerman H, de Groot V, et al. Long-term effect of comorbidity on the course of physical functioning in patients after stroke and with multiple sclerosis. *J Rehabil Med.* 2009;41(5):322-326.
40. Gulick EE. Emotional distress and activities of daily living functioning in persons with multiple sclerosis. *Nurs Res.* 2001;50(3):147-154.

The following issues of *MS Counseling Points*[™] are available at www.counselingpoints.com and www.iomsn.org:



- Helping People with MS to Improve Sleep Quality
- Answering Patients' Treatment-related Questions
- Preserving Quality of Life in MS
- Assessing and Addressing Disability in MS
- Modifying the Immune System in MS: What We Know, What We're Learning
- Injection-site and Skin-reaction Management
- Counseling Patients on Long-term Disease-modifying Therapy
- Update on Clinically Isolated Syndrome
- Emerging Therapies for MS
- Practical Approaches to Spasticity
- Brain Atrophy and Disability in MS

CP Counseling Points™

Treating the Whole Patient: Applying Comprehensive Care in MS

- A more complete understanding of the goals and objectives of comprehensive care in multiple sclerosis (MS) can help MS nurses determine whether changes are warranted in care delivery or overall philosophy to promote greater wellness and well-being for the person with MS.
- The goal of comprehensive care is to focus on the “whole person,” while the main goal of integrated care is to foster communication among members of the healthcare team.
- Many aspects of MS care make a comprehensive approach well suited, including the need to adjust the focus of care over the lifetime of the disease, the need to manage symptoms and comorbidities affecting multiple body systems, the need to maintain communication among team members, and the need for cost-containment in care delivery.
- Self-management, self-efficacy, well-being, and quality of life (QOL) can be vague concepts to define, but have become a greater focus of chronic care delivery in recent years, including in MS care. The patient-centered medical home is one model being explored in MS and other environments that emphasizes comprehensive care and inter-provider communication.
- Studies have suggested that people with MS tend to have lower QOL than people with other types of disabilities. As an aid for communicating with patients about QOL, MS clinicians can use a number of validated QOL assessment tools.
- In recent years, greater recognition has been given to the influence of comorbid medical conditions on MS. Comorbidities are distinct from MS symptoms, and may affect overall wellness, disability progression, and selection of treatments for MS.

Counseling Points™

Treating the Whole Patient: Applying Comprehensive Care 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% (9 correct) or better. A certificate will be mailed within 4 to 6 weeks. There is no charge for the CNE credit.

By Mail: Delaware Media Group, 66 S. Maple Ave., Ridgewood, NJ 07450

By Fax: (201) 612-8282

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

- The essential difference between the concepts of integrated care and comprehensive care is that integrated care:**
 - focuses on the whole person
 - fosters communication among the healthcare team
 - encompasses care of all groups regardless of race or religion
 - has been established as economically feasible
- In a comprehensive care model, the role of the patient is:**
 - a consumer of services
 - the object of a coordinated decision-making process by the healthcare team
 - an integral part of the healthcare team
 - the primary coordinator between specialty and primary care services
- In the Consortium of Multiple Sclerosis Centers' statement on comprehensive MS management, the initially higher costs of comprehensive care should be offset by:**
 - minimizing unpredictable changes associated with MS
 - reducing secondary complications
 - minimizing overlap of services
 - all of the above
- The concept of a patient-centered medical home (PCMH) refers to:**
 - homes adapted to accommodate future needs of disabled persons
 - a specialized medical center where all forms of medical care can be provided under one roof
 - a system of coordination of primary care and specialty care using electronic resources to involve the patient in care decisions
 - a practice that considers the patient to be the primary decision maker on medical care issues
- The best definition of "self-efficacy" is:**
 - belief in oneself that one's behavior can produce certain outcomes
 - ability to self-administer medications in order to achieve efficacious results
 - applying mind-over-matter in overcoming an illness
 - none of the above
- Stress management has been associated with the development of fewer new brain lesions in studies of patients with multiple sclerosis (MS).**
 - True
 - False
- Low quality-of-life (QOL) scores in MS have been shown to be associated with which of the following?**
 - Ability to work
 - Ability to pursue leisure activities
 - Ability to carry out life roles
 - All of the above
- QOL assessment tools validated for use in MS include all of the following EXCEPT:**
 - MSQOL-54
 - MMPI
 - Short Form SF-36
 - MS Modified Fatigue Impact Scale
- Strong predictors of poor QOL for people with MS include all of the following EXCEPT:**
 - female gender
 - cognitive impairment
 - lack of social support
 - chronic pain
- QOL is rarely used as an outcome in studies of MS disease-modifying therapies (DMTs) because it is too difficult to define and establish among large groups.**
 - True
 - False
- According to data from the NARCOMS Registry, people with MS have a prevalence of depression _____ relative to the general population:**
 - approximately the same
 - two times higher
 - three times higher
 - data are not available
- The safety of MS disease-modifying therapies (DMTs) in patients with medical comorbidities has been:**
 - studied extensively in clinical studies
 - not well studied because these patients are often excluded from trials
 - well established over time
 - established for young males but not for females or elderly persons

Counseling Points™: Program Evaluation Form

Treating the Whole Patient: Applying Comprehensive Care 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** or complete it online as instructed below.

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 the rationale for multidisciplinary management in MS and describe the principles of integrated care 5 4 3 2 1
- 2) Analyze the interrelationship between MS symptomatology and overall health 5 4 3 2 1
- 3) Describe approaches for integrating treatment, symptom management, and health and wellness in MS 5 4 3 2 1

To what extent was the content:

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

General Comments

8) 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

Request for Credit *(Please print clearly)*

Name _____ Degree _____

Organization _____ Specialty _____

Address _____

City _____ State _____ ZIP _____

Phone _____ Fax _____ E-mail _____

Signature _____ Date _____

By Mail: Delaware Media Group, 66 S. Maple Ave., Ridgewood, NJ 07450

By Fax: (201) 612-8282

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.

CP



www.delmedgroup.com