Summer 2014

Complimentary Continuing Education Credit for Nurses Volume 10, Number 1 Counseling Points

Enhancing Patient Communication for the MS Nurse

Management of MS Through the Life Stages

Series Editor

Amy Perrin Ross, APN, MSN, CNRN, MSCN

Faculty Panel

Cheryl Blaschuk, MSN, NP, MSRN Jennifer Boyd, RN, MHSc, MSCN Lori Mayer, DNP, MSN, RN, 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

Cheryl Blaschuk, MSN, NP, MSRN

Advanced Practice Nurse Prescriber Aurora Neuroscience Innovation Institute Milwaukee, WI

Jennifer Boyd, RN, MHSc, MSCN Clinical Nurse Specialist, Neurology Hospital for Sick Children Toronto, Ontario, Canada

Lori Mayer, DNP, MSN, RN, MSCN Director, Medical Research Services MS Clinic of Central Texas/Central Texas

Neurology Consultants Round Rock, TX

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 CNS.

Cheryl Blaschuk has disclosed that her spouse owns stock in Teva CNS.

Jennifer Boyd has disclosed no relevant financial relationships.

Lori Mayer has received honoraria for consulting and participating on the Speakers' Bureaus for Acorda Therapeutics, Biogen, EMD Serono, Novartis, Questcor, and Teva CNS.

Planners and Managers

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

Medical Writer Katherine Wandersee

Art Director

James Ticchio

Cover photo credit: © EpicStockMedia / Veer

Copyright © 2014, 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™ Management of MS Through the Life Stages Continuing Education Information

Target Audience

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

Purpose

To provide nurses with information about how changes due to life transitions and aging affect the care of MS.

Learning Objectives

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

- Discuss issues affecting younger patients with MS
- Assess challenges and health concerns occurring for patients with MS at different life stages
- Recognize shift in MS outcomes over time with improved disease management
- Describe health risks that increase among patients with MS during the aging process

Continuing Education Credit

This continuing nursing education activity is developed under the joint providership of 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 and reviewer for this activity. She has declared no relevant financial relationships.

This activity has been awarded 1.0 contact hours (0.25 contact hours are in the area of pharmacology). Code: MSCP08014.

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 August 31, 2015.

Disclosure of Unlabeled Use

This educational activity contains discussion of published and/or investigational uses of agents that are not approved by the FDA, including use of disease-modifying therapies in patients under 18 years of age. 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,

Multiple sclerosis (MS) can begin at any age, affecting young children as well as middle-aged and older adults. Importantly, the management of MS needs to be adapted as the patient's health and lifestyle practices change over time. Many health concerns of people with MS reflect those of society at large. For example, obesity and related comorbidities such as diabetes are observed increasingly in the MS patient population, often at younger ages than we saw in the past.

There are many other issues that we must consider as our patients age. For example, patients may not realize that ambulation difficulties—combined with hazards in the home and body changes due to aging—put them at increased risk for falls. As MS nurses, we often view ourselves as caring for the "whole patient." However, it is also important to emphasize the need for collaboration with other healthcare providers, especially as our patients become older and are affected by comorbid health conditions. Patient-care procedures such as checking bone mineral density and other standard tests are often best handled by primary care physicians or geriatricians, so we can focus on what we do best, which is managing MS-related conditions.

This issue of *MS Counseling Points* provides an overview designed to help the MS nurse anticipate and respond to health concerns at different life stages. Our MS nurse panelists bring expertise in pediatric MS, geriatric care, and overall MS management. It is encouraging to see our patients doing better as they age, as a result of advances in MS care and better overall management.

Omy former Ress

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

Management of MS Through the Life Stages

lthough multiple sclerosis (MS) usually strikes people between the ages of 20 and 40, nurses who work in the field of MS often see patients in a much broader range of age groups. Due to increased awareness and improved diagnosis, pediatric MS is more likely to be identified at its early stages.¹ In addition, older patients with MS are living longer and staying active longer due to improved overall healthcare and effective use of disease-modifying therapies (DMTs).^{2,3} Life-stage transitions are usually associated with changing needs and priorities, regardless of whether a person has a chronic disease or is relatively healthy. With a complex neurologic condition such as MS, there may be a tendency for healthcare professionals-and patients themselves-to focus on the disease and to disregard health matters that would affect any other individual. This issue of Counseling Points calls attention to some of the key issues that affect patients with MS at various life stages and during these transitional periods.

Pediatric MS

Pediatric MS has been described as an underrecognized and undertreated subgroup of MS, in part because of its relative rarity and relapsingremitting nature.⁴ Pediatric MS is defined as two or more episodes of central nervous system (CNS) demyelination in a patient younger than age 18, separated by more than 30 days and involving more than one area of the CNS.⁵ According to the National Multiple Sclerosis Society (NMSS), an estimated 8,000 to 10,000 children in the U.S. have MS, while another 10,000 to 15,000 have experienced at least one symptom suggestive of MS.⁶ Studies suggest that approximately 5% of all MS cases affect the pediatric population, primarily teens between the ages of 13 and 16.⁷ Diagnosis of MS in children under age 10 occurs in less than 1% (0.2% to 0.7%) of all cases of MS.^{8,9}

The presentation of MS in children is generally similar to that in adults, and may involve optic neuritis, hemisensory or hemimotor symptoms, transverse myelitis, brainstem symptoms (internuclear ophthalmoplegia, cranial nerve involvement, ataxia).¹⁰ Most children with MS present with a relapsing-remitting course and have good recovery from relapses, although residual effects may include decreased vision, ongoing sensory symptoms, and balance problems.¹¹

Differential diagnosis is especially important in children who present with symptoms of demyelinating disease, because a number of conditions may resemble MS, including neuromyelitis optica (NMO, or Devic's disease), CNS vasculitis, neoplasms, and leukodystrophies. Optic neuritis may be underreported in pediatric patients, particularly in younger children who are not able to describe their symptoms.¹² In addition, children are more likely than adults to present with acute disseminated encephalomyelitis (ADEM), a demyelinating disorder that is usually an isolated event.

In the U.S. there are currently 9 Centers of Excellence in pediatric MS designated by the NMSS (**Table 1**). In addition, there are 3 specialty pediatric MS clinics in Canada. Depending

Table 1. NMSS-designated Pediatric MSCenters of Excellence

Center for Pediatric-Onset Demyelinating Disease

Children's Hospital of Alabama Birmingham, AL

UCSF Regional Pediatric MS Center University of California San Francisco San Francisco, CA

Pediatric Multiple Sclerosis Center Loma Linda University Children's Hospital San Bernardino, CA

Partners Pediatric MS Center

Massachusetts General Hospital for Children/Yawkey Center for Outpatient Care Boston, MA

Pediatric Multiple Sclerosis and Related Disorders Program Boston Children's Hospital Boston, MA

Mayo Clinic Pediatric MS Center Rochester, MN

Pediatric MS Center of the Jacobs Neurological Institute Buffalo, NY

Lourie Center for Pediatric MS Stony Brook University Hospital Stony Brook, NY

The Blue Bird Circle Clinic for Multiple Sclerosis Texas Children's Hospital Houston, TX

upon the distance to these centers and other barriers, many pediatric patients with MS are unable to receive their regular care in a specialized pediatric MS clinic. Adult MS centers and pediatric or general neurologists are seeing an increasing number of pediatric patients with MS.^{10,13}

Although pivotal clinical trials of MS DMTs do not enroll patients under age 18, these treat-

ments are recommended for off-label use in current pediatric MS guidelines to limit progression of disease at the critical early stages.¹⁴ Some controlled clinical trials of MS DMTs have been performed in pediatric patient populations, including the trials summarized in **Table 2**.¹⁵⁻¹⁹

Key transitional issues: family involvement

When a child is diagnosed with MS, the role of the family is paramount in the support of the patient. Adherence to therapy requires that the family and patient accept the diagnosis and agree with the treatment plan. Poor adherence among children with MS can result from family conflicts or a difficult household environment, limited education about the disease, and an incomplete understanding about the purpose of therapy.²⁰ When patients reach their teens, there is usually a transition toward more independent decision making. MS nurses who care for young patients who are reaching their teen years need to be aware of the patient's wishes in this regard. Responsibility for adhering to treatments may shift to the patient, yet adherence rates have been shown to drop off as parental involvement is lessened.8 Resources for families are provided in Table 3.

Teens with MS

Being a teenager with MS is a particularly challenging situation. Relapses and MS symptoms such as fatigue may cause teens to miss school, cut back on social activities, and feel "different" from their peers at a time when they are just trying to fit in. Cognitive dysfunction has been shown to affect approximately one-third of children and adolescents with MS, and may interfere with academic achievement, including the ability to perform in standardized tests for college admissions.²¹ Medication adherence problems are often more prevalent among adolescents, who rebel

Study author (Year)	Disease-modifying therapy	Mean patient age, (number of patients)	Treatment duration (months)	Relapse rate reduction
Ghezzi (2007) ¹⁵	IFNB-1a IM	Age of MS onset, 11.7 yrs (N=52)	43	79%
Banwell (2006) ¹⁶	INFB-1b SC	Age at start of treatment, 13 yrs (N=43)	29	50%
Ghezzi (2005) ¹⁷	IFNB-1a IM IFNB-1a SC GA	Age of MS onset, 12.4 yrs (N=38) (N=16) N=9	23.3 40.7 33.3	83% 75% 91%
Tenembaum (2006) ¹⁸	IFNB-1a SC	(N=24)	44	(significant)
Kornek (2003) ¹⁹	GA	Age of MS onset, 9–16 yrs (N=7)	24	100%

Table 2. Trials of MS DMTs in Pediatric Patient Populations

because they want to feel "normal" and don't believe that the medications are necessary. As Mah and Thannhauser noted, "Adolescents' sense of omnipotence, cognitive limitations in assessing risks, and relative inexperience with long-term

Table 3. Resources for Families ofChildren with MS

The following resources are available as downloads from the National Multiple Sclerosis Society's website (www. nationalMSsociety.org) under Pediatric MS Support Network.

- Kids Get MS Too: A Handbook for Parents Whose Child or Teen has MS
- Managing School-Related Issues: A Guide for Parents with a Child or Teen Living with MS
- Your Education Rights as a Student with MS
- Alie's Fund for Children With MS (funding for patients ages 2 to 22 to assist young patients with MS)
- Connect With Other Families (Pediatric MS and Teen MS groups)

consequences (especially with an 'invisible' disease like MS) may lead to the belief that they do not need to follow the treatment plan."²¹

Psychosocial adjustment difficulties can be a significant concern for teens and younger adults with MS. At one pediatric MS center, major depression or anxiety disorders were identified in 6 of 13 adolescents studied (46%).²² Depression and anxiety may be related to the disease process, a psychological reaction to the diagnosis, or a combination of both. Amato et al reported that adverse behavioral changes were reported by parents in 39% of adolescents, including increased anxiety, aggression, and isolation.²³

In order to learn more about the experiences of adolescents living with MS, Boyd and MacMillan from the Pediatric MS Clinic at the Hospital for Sick Children in Toronto, Canada interviewed 12 patients between the ages of 8 and 18, focusing on key stressors, peer relationships, and adjusting to the diagnosis. The observations from this study are summarized in **Table 4**.¹¹

Table 4. Observations fromPsychosocial Studies of Teens With MS

Summary of findings from interviews with 12 pediatric patients with MS (ages 8 to 18) from the Pediatric MS Clinic at the Hospital for Sick Children, Toronto, Canada. Key issues identified were:

Stressors

Issues causing the most stress were unresolved symptoms, unpredictable relapses, missed school days, demanding treatment regimens, family conflicts, uncertain future

School

School difficulties were related to cognitive challenges or school absenteeism

Peers

Patients reported both positive and negative changes in peer relationships. Some relationships became stronger, others grew distant. Peer relationships were interrelated with the grief process

Identity

Some patients developed a new appreciation of life after over time after living with MS. Although MS brought significant life-changing experiences, many aspects of the patients' lives remained the same

Grief and coping

Adolescents vacillated between grief and acceptance with each loss experience. For some, this adjustment became easier with each subsequent loss. Others struggled with the challenge of shifting between grief and acceptance.

Adapted from: Boyd JR, MacMillan LJ. Experiences of children and adolescents living with multiple sclerosis. *J Neurosci Nurs*. 2005;37(6):334-342.¹¹

Key transitional issues: establishing independence

In the transition from adolescent to adult healthcare, the patient may need to adjust to a different care team with different approaches to care. Older teens will be expected to take on more responsibility for their healthcare decisions and for communicating with healthcare providers. Teens whose MS was diagnosed earlier in childhood may require re-education about their disease, since most of the earlier education was directed toward the parents. Teens and young adults will face new situations, such as deciding whether to disclose the diagnosis of MS to their friends, teachers, and employers.

Young Adults

Since the average age of onset for MS is about 30, much of the professional and patient education in MS focuses on the specific challenges faced by this population, such as career development, fertility and childbearing, and family issues.²⁴ Recent evidence suggest that people with MS are living healthier lives overall, and are being managed in the outpatient setting. A large study by Marrie and colleagues showed that hospitalization rates of people with MS declined by 75% during a 27-year study period, while those of a matched control group declined 41% (**Figure 1**).² In the study year 2011, the proportion of all hospitalizations that were due to MS was just 7.8%.²

At the same time, there are chronic health conditions that affect a greater proportion of patients. Obesity is a major concern affecting an increasing number of people with MS, as in the population as a whole. Data from several studies suggest that obesity is linked to MS pathogenesis, which may partly explain the increased incidence of MS in children.^{25,26} Obesity increases the rate of serious comorbidities-such as diabetes, other cardiovascular diseases, and arthritis-and makes the MS that much more difficult to manage. Mobility limitations and exercise intolerance are significant problems for people carrying added weight, and all the more so for patients with MS. As difficult as life-changing weight loss can be for anyone who is overweight, making this kind of dramatic change is especially difficult while coping with the diagnosis and day-to-day challenges of MS. While the MS



had developed a progressive course, 99% had done so by age 75 (or within 35 years after the onset of disease). In contrast, among patients with RRMS studied, 38% did not develop a progressive course by age 75, suggesting that this pattern would continue. Interestingly, for those who reached a progressive stage, this milestone was more closely related to the person's age than to how long they had the disease. These authors concluded that progressive MS is an age-dependent phenomenon, but that onset of a progressive phase is not

nurse may hesitate to raise the subject of weight loss soon after a person's diagnosis, this may be a good time to motivate these patients to try to help themselves and minimize complications of their disease by leading a healthier lifestyle.

Middle Age

One of the major concerns for patients with MS when they reach middle age is whether the person will reach a progressive stage of disease or have worsening disability. There is a belief that most people with relapsing-remitting MS (RRMS) will eventually reach a secondary progressive phase (SPMS), but this may not always be the case. Factors that influence the onset of a progressive course of disease in older adults were explored in a population-based study from the Mayo Clinic sponsored by the NMSS.²⁷ This analysis was based on 1,174 patients with MS (RRMS and progressive forms) from an Olmsted County, MN, database. The findings showed that for patients who inevitable as patients age. A significant proportion (more than one-third) will not reach SPMS.²⁷

The study also examined the onset of certain Expanded Disability Status Scale (EDSS) milestones and found that most patients (98%) do not reach the EDSS 6.0 until *after* they have stopped having relapses and have entered a progressive stage. Again, how quickly patients reached EDSS 6.0 was found to be more related to age than to how many relapses the patient had prior to reaching SPMS. A separate analysis of natural history data by Scalfari and colleagues concluded that "development of SP is the dominant determinant of long-term prognosis" in MS, and that this is independent of disease duration and frequency of early relapses.²⁸

Use of DMTs later in life

The question of whether a person should continue to use DMTs after many years with MS or after entering a progressive phase continues to be controversial. Studies of DMTs suggest that the role of these agents in patients with progressive MS is mainly to prevent an additional disability burden due to superimposed relapses.²⁹ However, because recent data suggest that many patients will continue to have RRMS without developing progressive disease, DMTs may be beneficial in the prevention of relapses even many years into the disease. Long-term follow-up studies have shown that many patients who stay on a DMT for extended periods (e.g., 20 or more years) do better than those not on treatment.^{30,31}

For example, the U.S. Glatiramer Acetate Trial followed patients who remained on GA therapy as their sole immunomodulating agent for as long as 15 years. Patients receiving continuous GA therapy had a mean disease duration of 22 years and a mean age of 50 years, yet two-thirds did not transition to a SPMS during the 15-year period. Over half (57%) had stable or improved EDSS scores and 82% remained ambulatory without the need for mobility aids.³⁰ Similarly, in a long-term trial of interferon beta-1b with 20 years of followup and high ascertainment rates, patients who had higher exposure to the study drug had a slower progression to EDSS 6.0 (13 years) compared with those who received treatment for shorter periods (7 years). The proportion of patients converting to SPMS was 45%.31

Older Adults with MS

Many older adults with MS did not have the benefit of DMT in the earlier stages of their disease. Some of these people are now in advanced stages of MS. However, we are also beginning to observe a shift, in which the people who received early treatment or who have been on therapy for many years are doing better, enjoying longer stretches of time without disability, and surviving longer overall. Natural history data

show that, when untreated, patients with MS have a decreased life expectancy averaging 6 to 12 years.³²⁻³⁶ However, those patients who were treated with DMTs (rather than placebo) in the earliest trials and have now been followed several decades have significantly improved life expectancy.37 Placebo-controlled trials of RRMS and clinically isolated syndrome (CIS) have shown that subjects who received therapy initially may have improved long-term outcomes, compared with those started on placebo and later moved to active therapy.38-40 Discussions about life expectancy and the impact of a disease state on survival commonly occur when patients have diseases such as cardiovascular disease or cancer, but in MS care we frequently avoid this discussion. When discussing prognostic issues with patients, it is essential to bear in mind that patients want better quality of life along with extended length of life.41-43

Lifestyle changes

As patients with MS get older and begin to accrue more disability, new health concerns can be anticipated. Caregiver burden is an important topic that often must be addressed at this time.44,45 In her research on the topic, Buhse has noted that, "caregiver burden is a multidimensional response to physical, psychological, emotional, social, and financial stressors."44 If the person with MS is married or has a life partner, that partner may face the challenges of actively working outside the home while helping to care for an aging family member with MS.46 In addition, these families may still be in the process of helping young adult sons or daughters, and/or providing care for aging parents. Some patients may need to consider increasing the level of care they receive in the home; others may need to move to a residential care facility. Some areas of the country offer an increasing number of options for a "middle

ground" of assisted living, but there are usually major expenses associated with these facilities. The added expense and responsibility of caring for a spouse or partner with advancing disabilities truly impacts the patient and the family both emotionally and financially.

Comorbidities

MS does not occur in isolation, and health conditions that affect the general population can just as easily afflict those with MS or even occur with greater frequency.⁴⁷ Patients may have a tendency to "blame the MS" for changes that may, in fact, be due to other health conditions. For example, joint pain due to osteoarthritis may cause mobility problems that the patient or other healthcare practitioners associate with MS. Gait adaptations over time may exacerbate wear and tear on certain joints. It's important for patients to be aware that surgery or other corrective procedures that may alleviate pain and enhance functioning are not off limits just because of MS. Many patients with MS can undergo surgery and spinal anesthesia.⁴⁸

"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.⁴⁷ Comorbidities may occur by chance, through common etiological mechanisms such as heredity, or via related risk factors (such as smoking). In some cases there is direct causation, in which one disorder leads directly to another.

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.⁴⁹ 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 people who did not have these comorbidities.⁵⁰

Prevention of falls

Falls are a key area of concern for any aging person, especially for people with MS. Both sexes may be at increased risk for osteoporosis—for women after they are postmenopausal, and for many men as a result of past steroid use.⁵¹ Transfers from chair to bed, toilet, etc. are a significant cause of falls for patients who are nonambulatory or have ambulatory limitations. The MS nurse may recommend a professional home assessment by a physical therapist to identify measures to help patients minimize the risk for falls.⁵²

Table 5 summarizes findings from an analysis based on Nationwide Inpatient Sample data over 20 years and involving more than 1 million hospital admissions for hip fractures.⁵² These data highlight the need to evaluate risk of falls and other

Table 5. Retrospective Cohort Analysis,Data from Nationwide InpatientSample52

Agency for Healthcare Research & Quality (AHRQ.gov)

1988–2007, iCD9 code for hip fracture and a secondary diagnosis of MS

- Of 1.06 million hip fractures identified, people with MS had 0.25%, representing a prevalence of ≥2 x that predicted based on population figures.
- People with MS were younger on average when hip fracture occurred (median age 65, vs. age 82 for non-MS population).
- People with MS had significantly lower mortality rates for hip fracture (0.25% vs. 2.97% for non–MS hip fracture patients).

fracture risk factors in patients with MS.

Clearly, the best time to conduct a home assessment is before a fall occurs, but this does not always happen because the patient is often not convinced that a PT home assessment is needed. Many patients do not recognize the potential problem, and will explain that they are "managing just fine."

Another adjustment that many patients with MS have difficulty accepting as they age is the use of assistive devices. Most people don't want to acknowledge that it's time to start using a cane, a walker, or a wheelchair. Because they resist trying, patients often fail to recognize the degree to which appropriate assistive devices can help them to get around better, accomplish more, and reduce fatigue. The initial device suggested is often a cane. However, it is important to recognize that canes not only require grip strength, but they hinder the use of one hand. Although walkers are among the most flexible assistive devices, they often have a bad reputation because of negative associations with being "elderly." Many people with MS can be convinced to try a walker by comparing it to a shopping cart. If patients can imagine the added support that holding onto a shopping cart provides as they push it through the store, they can potentially view the walker as similar, but more compact and portable.

Nurses may also help patients make decisions about whether to use a manual wheelchair versus a motorized wheelchair or scooter. If the patient elects to use a motorized device, he or she needs to consider factors such as the weight of the equipment, how it will be taken in and out of the house, the car, etc. Some patients find that a folding manual wheelchair that can easily fit in a car trunk offers more flexibility and allows them access to more places.

Key transitional issues: social support

Researchers have found that many older adults with MS become more adept at coping with aging-related changes over time.⁵³ Sufficient social support is a key aspect of how patients adapt and cope with these changes. Patients also do not appear to show accelerated rates of cognitive decline, and rates of some neuropathologic changes have been shown to normalize compared with those seen in normal aging. Results are mixed as to whether older MS patients have higher rates of depression.⁵³

Conclusion

There is an ongoing need for individualization of treatment and adjustment of the care plan as patients age and their priorities shift. The MS nurse should try to keep in mind these lifestyle transitions and help patients to adapt and adjust accordingly.

References

- Krupp LB, Tardieu M, Amato MP, et al. International Pediatric Multiple Sclerosis Study Group criteria for pediatric multiple sclerosis and immunemediated central nervous system demyelinating disorders: revisions to the 2007 definitions. *Mult Scler.* 2013;19(10):1261-1267.
- 2. Marrie RA, Elliott L, Marriott J, et al. Dramatically changing rates and reasons for hospitalization in multiple sclerosis. *Neurology*. 2014.
- Ploughman M, Beaulieu S, Harris C, et al. The Canadian survey of health, lifestyle and ageing with multiple sclerosis: methodology and initial results. BMJ Open. 2014;4(7):e005718.
- Patel Y, Bhise V, Krupp L. Pediatric multiple sclerosis. Ann Indian Acad Neurol. 2009;12(4):238-245.
- Krupp LB, Banwell B, Tenembaum S. Consensus definitions proposed for pediatric multiple sclerosis and related disorders. *Neurology*. 2007;68(16 Suppl 2):S7-12.
- 6. National Multiple Sclerosis Society. Pediatric MS. Available at: http:// www.nationalmssociety.org/What-is-MS/Who-Gets-MS/Pediatric-MS.
- Duquette P, Murray TJ, Pleines J, et al. Multiple sclerosis in childhood: clinical profile in 125 patients. J Pediatr. 1987;111(3):359-363.
- Renoux C, Vukusic S, Mikaeloff Y, et al. Natural history of multiple sclerosis with childhood onset. N Engl J Med. 2007;356(25):2603-2613.
- Ruggieri M, Iannetti P, Polizzi A, et al. Multiple sclerosis in children under 10 years of age. Neurol Sci. 2004;25 Suppl 4:S326-335.
- Chitnis T, Tardieu M, Amato MP, et al. International Pediatric MS Study Group Clinical Trials Summit: meeting report. *Neurology*. 2013;80(12):1161-1168.
- 11. Boyd JR, MacMillan LJ. Experiences of children and adolescents living with multiple sclerosis. J Neurosci Nurs. 2005;37(6):334-342.
- Pohl D, Rostasy K, Treiber-Held S, et al. Pediatric multiple sclerosis: detection of clinically silent lesions by multimodal evoked potentials. J Pediatr. 2006;149(1):125-127.
- 13. Reinhardt K, Weiss S, Rosenbauer J, et al. Multiple sclerosis in children and adolescents: incidence and clinical picture - new insights from the nationwide German surveillance (2009-2011). *Eur J Neurol.* 2014;21(4):654-659.
- 14. Chitnis T. Disease-modifying therapy of pediatric multiple sclerosis. Neu-

rotherapeutics. 2013;10(1):89-96.

 Ghezzi A, Amato MP, Capobianco M, et al. Treatment of early-onset multiple sclerosis with intramuscular interferonbeta-1a: long-term results. *Neurol Sci.* 2007;28(3):127-132.

- Banwell B, Reder AT, Krupp L, et al. Safety and tolerability of interferon beta-1b in pediatric multiple sclerosis. *Neurology*. 2006;66(4):472-476.
- Ghezzi A, Amato MP, Capobianco M, et al. Disease-modifying drugs in childhood-juvenile multiple sclerosis: results of an Italian co-operative study. *Mult Scler.* 2005;11(4):420-424.
- Tenembaum SN, Segura MJ. Interferon beta-1a treatment in childhood and juvenile-onset multiple sclerosis. *Neurology*. 2006;67(3):511-513.
- Kornek B, Bernert G, Balassy C, et al. Glatiramer acetate treatment in patients with childhood and juvenile onset multiple sclerosis. *Neuropediatrics*. 2003;34(3):120-126.
- MacAllister WS, Boyd JR, Holland NJ, et al. The psychosocial consequences of pediatric multiple sclerosis. *Neurology*. 2007;68(16 Suppl 2):S66-69.
- Mah JK, Thannhauser JE. Management of multiple sclerosis in adolescents - current treatment options and related adherence issues. *Adolesc Health Med Ther.* 2010;1:31-43.
- MacAllister WS, Belman AL, Milazzo M, et al. Cognitive functioning in children and adolescents with multiple sclerosis. *Neurology*. 2005;64(8): 1422-1425.
- 23. Amato MP, Goretti B, Ghezzi A, et al. Cognitive and psychosocial features of childhood and juvenile MS. *Neurology*. 2008;70(20):1891-1897.
- 24. Confavreux C, Vukusic S. Natural history of multiple sclerosis: a unifying concept. *Brain.* 2006;129(Pt 3):606-616.
- Hedstrom AK, Lima Bomfim I, Barcellos L, et al. Interaction between adolescent obesity and HLA risk genes in the etiology of multiple sclerosis. *Neurology*. 2014;82(10):865-872.
- 26. Versini M, Jeandel PY, Rosenthal E, et al. Obesity in autoimmune diseases: Not a passive bystander. *Autoimmun Rev.* 2014.
- Tutuncu M, Tang J, Zeid NA, et al. Onset of progressive phase is an age-dependent clinical milestone in multiple sclerosis. *Mult Scler*. 2013;19(2):188-198.
- Scalfari A, Neuhaus A, Daumer M, et al. Age and disability accumulation in multiple sclerosis. *Neurology*. 2011;77(13):1246-1252.
- Kappos L, Weinshenker B, Pozzilli C, et al. Interferon beta-1b in secondary progressive MS: a combined analysis of the two trials. *Neurology*. 2004;63(10):1779-1787.
- Ford C, Goodman AD, Johnson K, et al. Continuous long-term immunomodulatory therapy in relapsing multiple sclerosis: results from the 15-year analysis of the US prospective open-label study of glatiramer acetate. *Mult Scler.* 2010;16(3):342-350.
- Ebers G, Rice G, Konieczny A, et al. The interferon beta-1b 16-year longterm follow-up study: the final results. Neurology. 2006;66(Suppl 2):A32.
- Kingwell E, van der Kop M, Zhao Y, et al. Relative mortality and survival in multiple sclerosis: findings from British Columbia, Canada. J Neurol Neurosurg Psychiatry. 2012;83(1):61-66.
- Bronnum-Hansen H, Koch-Henriksen N, Stenager E. Trends in survival and cause of death in Danish patients with multiple sclerosis. *Brain*. 2004;127(Pt 4):844-850.
- Leray E, Morrissey SP, Yaouanq J, et al. Long-term survival of patients with multiple sclerosis in West France. *Mult Scler*. 2007;13(7):865-874.
- 35. Smestad C, Sandvik L, Celius EG. Excess mortality and cause of

death in a cohort of Norwegian multiple sclerosis patients. *Mult Scler.* 2009;15(11):1263-1270.

- Sumelahti ML, Hakama M, Elovaara I, et al. Causes of death among patients with multiple sclerosis. *Mult Scler.* 2010;16(12):1437-1442.
- Goodin DS, Reder AT, Ebers GC, et al. Survival in MS: a randomized cohort study 21 years after the start of the pivotal IFNbeta-1b trial. *Neurology*. 2012;78(17):1315-1322.
- Randomised double-blind placebo-controlled study of interferon beta-1a in relapsing/remitting multiple sclerosis. PRISMS (Prevention of Relapses and Disability by Interferon beta-1a Subcutaneously in Multiple Sclerosis) Study Group. *Lancet.* 1998;352(9139):1498-1504.
- Kappos L, Freedman MS, Polman CH, et al. Long-term effect of early treatment with interferon beta-1b after a first clinical event suggestive of multiple sclerosis: 5-year active treatment extension of the phase 3 BEN-EFIT trial. *Lancet Neurol.* 2009;8(11):987-997.
- Comi G, Martinelli V, Rodegher M, et al. Effect of glatiramer acetate on conversion to clinically definite multiple sclerosis in patients with clinically isolated syndrome (PreCISe study): a randomised, double-blind, placebocontrolled trial. *Lancet*. 2009;374(9700):1503-1511.
- 41. Crayton HJ, Rossman HS. Managing the symptoms of multiple sclerosis: a multimodal approach. *Clin Ther.* 2006;28(4):445-460.
- Janssens AC, van Doorn PA, de Boer JB, et al. Impact of recently diagnosed multiple sclerosis on quality of life, anxiety, depression and distress of patients and partners. Acta Neurol Scand. 2003;108(6):389-395.
- 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.
- 44. Buhse M. Assessment of caregiver burden in families of persons with multiple sclerosis. *J Neurosci Nurs.* 2008;40(1):25-31.
- Buhse M, Banker W, Clement L. Health related differences among elderly MS patients with and without a caregiver. *Neurology*. 2012;78(Meeting Abstracts 1): P06.162.
- Buhse M, Banker WM, Clement LM. Factors associated with healthrelated quality of life among older people with multiple sclerosis. Int J MS Care. 2014;16(1):10-19.
- Marrie RA, Horwitz RI. Emerging effects of comorbidities on multiple sclerosis. Lancet Neurol. 2010;9(8):820-828.
- 48. McSwain JR, Doty JW, Wilson SH. Regional anesthesia in patients with pre-existing neurologic disease. *Curr Opin Anaesthesiol.* 2014.
- 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.
- 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.
- 51. Gibson JC, Summers GD. Bone health in multiple sclerosis. Osteoporos Int. 2011;22(12):2935-2949.
- Bhattacharya RK, Vaishnav N, Dubinsky RM. Is there an increased risk of hip fracture in multiple sclerosis? Analysis of the Nationwide Inpatient Sample. J Multidiscip Healthc. 2014;7:119-122.
- Gray V, Arnett P. Aging with multiple sclerosis: cognitive, emotional and neuropathological considerations. *Neurodegener Dis Manag.* 2014;4(2):187-194.

Counseling Points^{IM}

Management of MS Through the Life Stages

- Pediatric multiple sclerosis (MS), defined as diagnosis before age 18, comprises approximately 5% of all cases. An estimated 8,000 to 10,000 children in the U.S. have MS, while another 10,000 to 15,000 have experienced at least one symptom suggestive of MS.
- When a child is diagnosed with MS, the role of the family is paramount in the support of the patient. When patients reach their teens, there is usually a transition toward more independent decision making.
- Being a teen with MS is a particularly challenging situation. Relapses and MS symptoms such as fatigue may cause teens to miss school, cut back on social activities, and feel "different" from their peers at a time when they are just trying to fit in.
- Patients entering young adulthood will face the challenges of MS in conjunction with career development as well as raising a family. Recent trends observed in this population include a decrease in acute hospitalizations for MS and other conditions, but a growth in chronic health conditions such as obesity and its complications.
- As they approach middle age, some patients may reach the point where their disease course is at a progressive stage. At the time when patients with MS get older and begin to accrue more disability, health concerns related to aging can be anticipated.
- Falls are a key area of concern for any aging person, especially for people with MS. Transfers from chair to bed, toilet, etc. are a significant cause of falls for patients who are nonambulatory or have ambulatory limitations.
- The MS nurse may recommend a professional home assessment by a physical therapist to help patients minimize the risk for falls. Nurses may also need to encourage patients to try assistive devices, which they may resist because of negative associations with old age or disability.
- There is an ongoing need for individualization of treatment and adjustment of the care plan as patients age and their priorities shift. The MS nurse should try to keep in mind these lifestyle transitions and help patients to adapt and adjust accordingly.

Counseling Points[™] Management of MS Through the Life Stages

Continuing Education Post-test

To receive contact hours, please read the program in its entirety, answer the following post-test 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 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 post-test and application forms.

PLEASE SELECT THE BEST ANSWER

- 1. Pediatric multiple sclerosis (MS) is described as MS occurring when patients:
 - a. are diagnosed prior to age 18
 - b. are diagnosed prior to age 13
 - c. have onset of symptoms before age 18
 - d. have onset of symptoms before age 13
- 2. In the differential diagnosis of pediatric patients with demyelinating disease, a condition frequently mistaken for MS is:
 - a. Lyme disease
 - b. spinal stenosis
 - c. Guillian Barre syndrome
 - d. acute disseminated encephalomyelitis
- 3. The recommended approach to treatment for patients with a confirmed diagnosis of pediatric MS is:
 - a. treat only with symptomatic agents
 - b. begin off-label treatment with disease-modifying therapy
 - c. treat only patients age 13 and over
 - d. use disease-modifying therapies approved for pediatric patients
- 4. Adherence problems in teens with MS have been shown to be related to:
 - a. a sense of invincibility
 - b. cognitive disability
 - c. inability to grasp long-term consequences of the disease
 - d. all of the above
- 5. Which of the following statements is *true* regarding hospitalization rates among adults with MS over a 27-year-period?
 - a. hospitalization rates increased because more patients survived longer with the disease
 - b. hospitalization rates decreased by 25% due to better overall care in MS
 - c. hospitalization rates decreased by 75% but chronic conditions increased
 - d. hospitalization rates decreased at the same proportion as controls without MS
- 6. Among patients with MS who survive to age 75, relapsing-remitting MS (RRMS) evolves into secondary progressive MS (SPMS) in approximately what proportion?
 - a. 100% of patients
 - b. 95% of patients
 - c. 60% of patients
 - d. 40% of patients

- 7. Data from long-term clinical trials of DMTs in MS suggest that long-term treatment:
 - a. may slow the rate of progression to SPMS
 - b. is not necessary as long as patients are treated for at least 5 years
 - c. reduces relapse rates in RRMS but has no effect on disability
 - d. is effective primarily in patients do not develop progressive disease
- 8. Recent data on long-term survival in MS have shown that:
 - a. MS increases disability but does not affect survival rates
 - b. survival rates are reduced by 6 to 12 years in untreated patients c. treatment with DMT early in the disease state may increase sur-
 - vival rates
 - d. both b and c above
- 9. Comorbidities associated with more rapid progression of ambulatory disability in people with MS include:
 - a. cognitive dysfunction and dementia
 - b. vascular diseases
 - c. major depressive disorder
 - d. none of the above
- 10. Situations associated with increased risk of falls in patients with MS include:
 - a. increased prevalence of osteoporosis
 - b. lack of patient education about reducing risk factors
 - c. need for transfers of nonambulatory patients
 - d. all of the above
- 11. Agency for Healthcare Research & Quality (AHRQ) data show that hip fractures:
 - a. occur mainly in patients with MS over age 65
 - b. occur mainly in patients who have received long-term steroidsc. occur at a younger age in MS compared with the general population
 - d. occur at lower rates in patients with MS over age 65 because most of these patients are in a wheelchair
- 12. Patients with MS who are reluctant to try an assistive device as they age should be encouraged to:
 - a. go to a wheelchair to prevent wear and tear on their joints
 - b. start out with a cane because they are smaller and relatively unobtrusive
 - c. wait until they are a bit older and really need the device, so they don't become dependent
 - d. be open-minded about how the device may broaden their abilities

Counseling Points[™]: Program Evaluation Form

Management of MS Through the Life Stages

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 appro	priate number on the scale.)					
) Discuss issues affecting younger patients with MS						
2) Assess challenges and health concerns occurring for patients with MS	at different life stages					
3) Recognize shift in MS outcomes over time with improved disease ma	inagement					
4) Describe health risks that increase among patients with MS during the	aging process					
10 what extent was the content:	5 4 2 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						
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 pract The program reinforces my current practice. Please indicate any barriers you perceive in implementing these Cost Lack of opportunity (patients) Lack of administrative support Reimbursement/insurance Lack of time to assess/counsel patien 	ice. changes (check all that apply): Patient adherence issues Cother (please specify) Lack of professional guidelines Mo barriers					
 11) Will you attempt to address these barriers in order to implement Types. How? Not applicable No. Why not? Suggestions for future topics/additional comments: 	it changes in your knowledge, skills, and/or patients' outcomes?					
Follow-up						
As part of our continuous quality-improvement effort, we conduct tional interventions on professional practice. Please check one: Yes, I would be interested in participating in a follow-up sur No, I would not be interested in participating in a follow-up	postactivity follow-up surveys to assess the impact of our educa- vey. o survey.					
There is no fee for this educational activity.						
Post-test Answer Key	5 6 7 8 9 10 11 12					
Request for Credit (Please print clearly)						
Name	Degree					
Organization	Specialty					
Address	· ·					
City	StateZIP					
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 post-test and evaluation forms.





www.delmedgroup.com