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# Multiple Sclerosis Among Rural Residents: Treatment, Psychosocial Implications, and Vocational Implications

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**Overview**
Multiple sclerosis (MS) is chronic, neurologic condition that generally affects individuals in their most fruitful working years (20–30 years old). Although the medical community is continually advancing novel treatments for MS, there is no cure, and one is not expected in the near future. The challenge for those with MS is to find effective interventions to ameliorate the symptoms associated with MS, which may allow them to remain functional and retain a good quality of life. Most individuals with MS have employment histories, but many choose to leave the workforce as a result of their symptoms (e.g., depression, fatigue, mobility), but literature indicates that the majority would like to return to work if possible.

Because of the lack of available resources in rural communities, those with MS are frequently underserved. Rural communities often lack specialty care (e.g., neurologists, physical therapists, occupational therapists, counselors), which are all necessary for the overall well-being of people with MS. Rehabilitation counselors (RCs), who view individuals holistically, are uniquely positioned to offer services that can improve both employment and quality of life for those with MS. RCs can serve as a point of contact and a source of information that can assist individuals in learning about MS and identifying problematic symptoms. An important consideration for RCs is that without addressing the accompaniments of MS, employment will remain precarious.

**Learning Objectives**
By the end of the chapter, the reader should be able to:

1. Understand the nature and course of MS and its symptomatology
2. Explain the challenges faced by individuals with MS living in rural areas
3. Have an understanding of the MS self-management scale and its importance to individuals with MS

## Introduction

Multiple sclerosis (MS) is a chronic, progressive, autoimmune demyelinating disease of the central nervous system affecting approximately

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1 in 750 people in the United States or about 400,000 American at any one time (Fraser, Kraft, Ehde, & Johnson, 2006; National Multiple Sclerosis Society [NMSS], 2015). MS affects about 2.3 million people worldwide; some nationalities seem greater affected than others (Browne et al., 2014). The typical course of MS is characterized by alternating episodes of neurological symptoms and remissions, with symptomatic phases including fatigue, mobility limitations, cognitive impairments, affective disorders, visual impairments, bowel and bladder dysfunction, and sexual dysfunction. MS symptoms frequently intensify over time, leaving the person with increased physical disability and declining general health (Buchanan, Wang, Martin, & Ju, 2006). Although the physical effects of MS are typically considered the primary source of disability, the consequences of the disease on affective well-being are equally important and frequently overlooked (Moore et al., 2012). MS is one of the most commonly diagnosed neurological conditions in North America and the leading nontraumatic cause of nervous system disabilities in young adults (Myhr, 2008).

MS is a disease that typically strikes younger individuals, usually in their late 20s or early 30s, when the first signs of the disease become evident. Following the initial onset of symptoms, functional and physical decline will progress over the next 30–40 years of life (Pugliatti et al., 2006). As a result of the previously mentioned sequela of MS and the challenges associated with effective and efficient care, those with MS require more services while also reporting greater unmet health-care needs when compared to other disabilities (Pohar, Jones, Warren, Turpin, & Warren, 2007). Because of the multitude of functional implications associated with MS, family members, friends, and paid caregivers are often needed to assist individuals with activities of daily living (Gottberg et al., 2008). In addition to the assistance frequently required to complete daily activities, people with MS report additional barriers regarding the availability of services in their community. Transportation services are commonly noted to be of importance for many people with MS due to inconsistent or lack of driving ability. Moreover, literature indicates that individuals living in rural areas have limited access to health-care and specialty services making transportation difficult due to long travel distances to access proper care. For those with MS living in rural communities, the issue of transportation is compounded. The unavailability of public transit, paratransit, and other modes of transportation results in greater challenges (see Chap. 3). Another identified concern is the availability and accessibility of home health services. Due to the increased functional limitations associated with the progressive nature of MS and the transportation barriers, inadequate home health services may not only affect proper care but may also result in people with MS losing their independence associated with living at home and may lead to one having to move into a long-term care facility (e.g., Galushko et al., 2014).

Although most people with MS express the above needs, it is clear that equitable services are not routinely available to all. Rural residents with MS are more likely to have unmet service needs resulting in additional challenges to receiving comprehensive care. The necessity of having access to a neurologist has been identified as a primary concern for individuals with MS. Unfortunately those with chronic conditions living in rural communities typically live in areas that are already drastically underserved (Wilper et al., 2008). Therefore, providing individuals with MS the essential high-quality primary and specialty care (e.g., physical therapy, occupational therapy, neurology) continues to be confounding. MS centers, arguably the most advanced care, are commonly located in larger, metropolitan cities where major universities reside, which preclude many in rural communities from receiving the most up-to-date treatments.

## Psychosocial Aspects

Literature suggests that many (55%) with MS require assistance walking, 50% need assistance from others to perform personal care activities, and roughly 60% require assistance with activities of daily living (Bishop, Rumrill, & Timblin, 2016;

Bishop et al., 2013; Davis & Tyry, 2008). The course of MS varies from person to person, and the symptoms are wide-ranging, affecting nearly every aspect of one's life (e.g., employment, social interactions, leisure activities; Antao et al., 2013). In addition to the physiological symptoms of MS, cognitive and affective associations are also significantly identified. Research suggests that 60–65% of individuals with MS have challenges with attention, conceptual reasoning, executive functioning, social judgment, and memory (Polman, Thompson, Murray, Bowling, & Noseworthy, 2006). Among the potential affective complications associated with individuals with MS, depression is the most common and potentially the most debilitating accompaniments with 50% experiencing at least one major depressive episode throughout the course of the disease (McReynolds & Koch, 2001). Adjusting to the constantly changing presentation of MS is one of the overriding challenges for individuals and their families.

## Caregivers

Because of the unpredictability of MS, caregivers are faced with not knowing when additional help may be necessary or how to effectively administer such assistance. Caregivers carry a significant amount of responsibility for their loved ones with MS but receive limited help from health-care professionals (Labiano-Fontcuberta, Mitchell, Moreno-García, & Benito-León, 2014). Therefore, not only is addressing the needs of the person with MS important, but also providing appropriate interventions to ensure that caregivers remain well and able to provide the necessary assistance is a key to maintaining health and family involvement. Family and caregivers are intimately involved in helping their loved ones cope with the physical and psychosocial effects of the disease and can frequently result in caregiver "burnout." One of the reported benefits of living in rural communities is that rural individuals are more likely to have a social network that will help with these needs if asked versus urban dwellers (Golla, Malhotra, Nanda, & Mehra, 2011). Rural communities have a tradition of helping neighbors in need but often feel unqualified to help. Rehabilitation professionals can assist by disseminating information to communities. Getting information about MS to caregivers or community friends may be best achieved through the Internet, community media, and other local resources (e.g., Buchanan, Huang, & Crudden, 2012); however, the level of availability of the Internet is a concern (see Chap. 4). Given the complex physical, psychological, and social impact of MS on the lives of both patients and caregivers, identifying what patients and caregivers perceive to be unmet needs, particularly in rural communities, is warranted.

In the United States, more than one in five adults provides unpaid care to another adult age 18 or older. In rural areas, the majority of caregivers are married, women, and white, have low income, have children or grandchildren, live within a 1-h drive of the care recipient, have provided care for 10 years or more, and spend an average of 21 h per week caregiving (Easter Seals Disability Services & National Alliance for Caregiving [ESDANAC], 2006). Caregivers report the following unmet needs: (a) finding time for oneself, (b) managing emotional and physical stress, and (c) balancing work and family responsibilities. In addition, caregivers report needing help in keeping the care recipient safe, finding easy activities to do with them, talking with doctors and other health-care professionals, or making end-of-life decisions. To provide care, rural caregivers have had to make workplace accommodations including taking time off and/or leave their job early, taking a leave of absence, dropping from full-time to part-time employment, turning down a promotion, taking early retirement, losing some job benefits, and giving up work entirely (ESDANAC). The impact on rural caregivers and care recipients is usually a reduced standard of living and increased stress.

## Social Involvement

The unpredictable and progressive nature of MS can have a significant effect on an individual's social involvement. We have discussed a number of functional changes associated with MS (e.g., mobility, bowel and bladder control) that can present significant challenges for individuals with MS to maintain their previous level of participation in social and community activities (e.g., sports, religious). Fatigue is commonly reported by individuals with MS, and two-thirds of people report that it negatively affects their ability to fulfill social and employment responsibilities (Berger, Pocoski, Preblick, & Boklage, 2013) As a result of the decrease in social involvement, many individuals with MS may suffer social isolation. Additionally, stigma and discrimination may contribute to one's decision to restrict activities outside the home (Halper, 2007). In rural areas, mobility issues are often a community issue as much as an individual one. Mobility is a common impairment for people with MS, and it has been estimated that within 10–15 years of an initial diagnosis of MS, approximately 80% of patients will experience some degree of impaired mobility (Souza et al., 2010).

Because friends and services essential for daily life are further away in rural communities, without appropriate interventions, the lack of mobility can lead to isolation. Rehabilitation professionals need to be aware of the importance of social interaction on the well-being of individuals with MS and be prepared to provide optimal support.

## Employment

Not only does MS affect one's family, caregivers, and social involvement, there is a deleterious impact on employment. Most individuals with MS experience the onset of symptoms in the height of their employment careers, but only a minority of individuals maintain employment following their initial diagnosis (Roessler, Neath, McMahon, & Rumrill, 2007). Of the individuals with MS who are unemployed, 75% claim they would like to return to work (Rumrill, 2006). Research indicates that employment is correlated with "well-being and quality of life, and provides access to economic security, increased opportunities for social participation, and access to health insurance and health care" (Chiu, Chan, Bishop, da Silva Cordoso, & O'Neill, 2013, p. 1656). Living in a rural community creates additional barriers to employment such as (a) fewer employment options, (b) employer discrimination, and (c) inadequate transportation. Frequently, individuals living in rural areas commute to metropolitan communities to find suitable employment, which is a challenge for individuals with MS. The profession of vocational rehabilitation counselor emphasizes "individual" plans for employment and education with the individual being the director of all plans. The field understands that without person-centered employment planning and the support of significant others, the plan will likely fail.

## Medical

With pioneering spirits and independence continuing to thrive in rural areas, health-care providers would be wise to understand rural culture, belief systems, values, and contextual factors into health-care programs and services. Health-care professionals should adopt the approach that rural individuals will choose whether to accept health care and not blindly comply with health-care directives. Understanding the importance of the self-management of one's MS, Bishop and Frain (2007) developed the Multiple Sclerosis Self-Management scale (MSSM) , which provides a method of assessing self-management knowledge and behavior among adults with MS. Rural individuals with MS can use the tenants of the MSSM, self-management, perception of control, and awareness, by understanding how adherence levels affect personally important aspects of life (e.g., ability to work, ability to fulfill life roles). Taking medication in order to extend one's life may matter less to a rural farmer than taking medication that allows them to be healthy enough to complete their duties on the farm.

Health-care services are more effective when tailored to fit within the schedules of those living and working in rural communities because many rural inhabitants frequently avoid health care until necessary functions have been fulfilled (Weihart & Long, 1987). Ranchers, farmers, and other occupations, which are more typical in rural environments than urban settings, often come with no paid days off and no health insurance. The ability to take care of health concerns during planting season is not realistic, just as taking time off on April 14 is not an option for a tax accountant. Health-care professionals who are outsiders and come into rural settings and attempt to impose their will on the community will often find a community chooses to seek other health-care options. It may take 5–10 years to be accepted as a regular part of the community for health-care professionals much different than the ever-changing caseload often seen in an urban setting. Health-care providers have an opportunity to provide instruction and relief for individuals and family members and frequently may be the sole professional providing care for individuals with disabilities and/or chronic illnesses. Trust and confidence are especially essential in rural communities, and because there is limited emigration, rural inhabitants develop strong relationships and are cautious of those from metropolitan areas. This creates challenges for rehabilitation counselors who cover broad geographic areas that include rural communities because they, too, are viewed with skepticism.

## Self-Management

Self-management has become recognized as a beneficial strategy for improving physical and psychological well-being and quality of life for individuals with chronic health conditions (Bycroft & Tracey, 2006; Lorig & Holman, 2003). Self-management may be loosely defined acquiring and implementing the skills needed to carry on a physically and emotionally satisfying life despite chronic conditions (Lorig, 1993). MSSM attempts to discover a number of dimensions of particular importance to individuals with MS and includes (a) treatment adherence and barriers, (b) knowledge and understanding of MS, (c) daily management of one's MS, (d) actively participating in health-care decision-making, and (e) managing the impact of MS on physical, emotional, and social life (Bishop & Frain, 2011). Research clearly elucidates the benefits of self-management and its associations with positive health and rehabilitation outcomes including (a) increased perceived control over both illness and nonillness aspects of one's life (Bishop, Frain, & Tschopp, 2008; Devins & Shnek, 2000); (b) reduced hospitalizations and medication expenses (Lorig, Ritter, Laurent, & Plant, 2006); (c) improved quality of life (Cochran & Conn, 2008); (d) decreased disability, anxiety, and health-care utilization; and (e) increased psychological well-being (Foster, Taylor, Eldridge, Ramsay, & Griffiths, 2007; Kennedy et al., 2007).

MSSM, as a theory, helps rehabilitation counseling professionals to understand the choices being made by rural individuals and, through education, gives the power for making self-management and treatment decisions to the individual. One potential issue particularly salient to individuals living in rural areas is how to access information pertinent to MS. Frequently, rural areas lack broadband services allowing community member to access the Internet, which is one of the most often cited methods for acquiring information. Additionally, because of the lack of specialty providers and the overreliance on primary care professionals to manage chronic illnesses, the potential exists for inadequate information. Rehabilitation counselors have both a charge and an opportunity to bridge the knowledge gap by providing guidance and information to rural residents. One important barrier to be addressed is getting health-care and illness-specific information into rural communities, which is addressed in detail in Chap. 29.

The SMSS model fits well with the belief systems that are prevalent in rural communities concerning the desire to be self-sufficient and the belief individualism regarding decisions about personal well-being. For this model to work in rural communities, rehabilitation counselors and other health professionals need to work collaboratively with people with MS using a person-centered approach. In order for persons with MS to self-manage their illness, they must first have the belief system and confidence they have the ability to control their life (Thompson, 2002). In rural communities, this belief system is generally in place; health-care professionals need to draw the parallels between taking care of their farm and taking care of their MS. Because rural citizens often think of health in more black and white terms of being able to work or not work, professionals should emphasize self-management to understand if one can work on a particular day or needs to rest. With a deeper understanding of the signs and symptoms of MS, people can gain confidence in what the body symptoms are telling them about the ability to do work. Over time, this higher level of perceived control over the illness has led to reduced anxiety and depression, better physical health, reduced impairment in daily living, higher levels of subjective well-being, and an increased likelihood that an individual will take action to improve or protect their physical health (Affleck, Tennen, Pfeiffer, & Fiffield, 1987; Bandura, 1997; Carver et al., 2000; Endler, Kocovski, & Macrodimitris, 2001).

## Communication with Health-Care Provider

Rural communities are more likely to make a decision after receiving input from others who are involved in the situation. For people with MS, this means that important life decisions (e.g., staying at work, home health care, moving to assisted living) result from gathering information and opinions from significant others. These may, indeed, include a variety of health-care providers (e.g., primary care physician, physical therapist, occupational therapist, neurologist) and may include those with whom the individual has significant relationships. Deciding to be open with health-care providers regarding symptoms and limitations requires collaboration and trust by both parties involved. Past research has indicated that those who have a trusting relationship with their treatment team and are in agreement with the approach to treatment fare much better than those who have a more distant and skeptical relationship (Bishop & Frain, 2007). As a result of the heterogeneous and inconsistent course of MS, communication between patient and provider is essential. There is no one-size-fits-all treatment regimen for individuals with MS, but well-informed health-care professionals can more effectively advise individuals of potential challenges and prepare patients to address them. Ultimately, to be effective, acculturation of health-care providers into rural communities in an attempt to garner trust and assume to role as an insider will likely produce more productive collaborative care.

## Treatment Adherence

Compliance with medical advice, like any decision, is personal, and individuals have a variety of reasons for opting to not adhere a provider's treatment plan. Adherence refers to the extent to which an individual follows the health-care professionals' orders/advice given to the patient such as diet, exercise, medications, and other health-care behaviors. One of the most widely researched topics concerning compliance addresses adherence to prescribed medications. According to the World Health Organization (WHO, 2003), improved treatment adherence would have a greater impact on health than most treatment advances. Research indicates that among non-MS treatment groups, medication adherence rates range from 25% to 50% Bosworth, 2006), and for individuals with MS, adherence ranges from 27% to 41% (Turner, Williams, Sloan, & Haselkorn, 2009). Clearly, nonadherence to treatment regimens may result in increased morbidity and decreased quality of life.

Reasons for treatment nonadherence vary greatly, but several common factors include (a) lower education, (b) increased disability, (c) perceived lack of efficacy, (d) lack of physician support, and (e) side effects (Bruce, Hancock, Arnett, & Lynch, 2010). Considering that individuals in rural communities have lower levels of education and there are fewer providers, one can understand why adherence may be even higher in these areas. A couple of factors not included in the previous list that certainly have an impact on adherence are medication costs and lack of health insurance. Again, incomes tend to be lower, on average, in rural communities, and due to higher rates of unemployment, fewer individuals have insurance coverage than those in urban areas. As previously described, openness with one's providers is critical to receiving appropriate care, and literature supports the positive correlation between individuals who are comfortable speaking candidly with their providers and treatment adherence (Bruce et al., 2010). Rural people with MS have expressed that the needs of their work, sometimes farm related, come before the need to take medication that may help in the long run. A frank discussion regarding the necessity of following a given treatment plan, why a certain medication was chosen, and ensuring that the individual understands the pros and cons is critical in an attempt to increase adherence and more positive outcomes.

## Social Support

Social support includes the supportive input that people receive from his/her social environment. Social support generally addresses three basic needs of an individual – emotional, instrumental (e.g., helping), and informational (Krokavcova et al., 2008). Social support not only impacts treatment adherence and overall quality of life, it is well documented that rural culture affects the health-care behaviors and the environmental factors of health in rural health settings (e.g., Stein, 1982; Stein & Pontious, 1985). Geographical dispersity of individuals in rural communities has been cited as the main factor in whether people are able to self-manage their health conditions (Winters, Cudney, Sullivan, & Thusen, 2006). Although there is a paucity of resources available for individuals with MS who live in rural communities, social support remains ubiquitous. Many residents have developed long-standing relationships and have spent their entire lives in a community where helping one another is a deeply engrained moral imperative. Considering this, when an individual acquires a chronic illness or disability, which severely limits mobility, the geographic distance can severely affect one's ability to engage socially.

Social support encompasses many different areas in self-management of MS. Specifically, social support was one of the factors posited to be positively associated with self-management (Bishop & Frain, 2011). The family unit including spouses and other live-in caregivers can be instrumental to providing for the support needs of someone with MS. Peer support networks have also demonstrated to be beneficial in helping individuals obtain answers to questions and serving as a guide for symptoms and disease expectations. Peer support groups, in particular, may be limited in rural areas simply due to the lack of resources and low numbers of individuals diagnosed with MS.

## Knowledge of MS

The stereotype of rural dwellers is they are industrious – when they have a problem they fix it and when they don't know how to fix something, they learn how. That spirit encompasses the very essence of self-management. Health literacy, the ability of people to gather, process, and make appropriate decisions regarding health information, is frequently discussed in extant literature, and its role in positive health outcomes is clear (Mackert, Ball, & Lopez, 2011). Knowledge about MS or any disease is one of the most empowering factors associated with positive outcomes. Considering the lower educational levels on individuals living in rural communities, achieving acceptable health literacy will take a concerted effort of all stakeholders involved in one's care. Additionally, low health literate individuals often find understanding a physician's explanation of their illness challenging, which results in poor health outcomes (Schillinger, Bindman, Wang, Stewart, & John, 2004). Because individuals may receive health information from a variety of sources, it is critical that providers be cognizant of those with low health literacy, provide clear interpersonal communication and readable and clearly understood handouts, and allow extended time to answer all questions (Mackert et al., 2011).

Although individuals with MS are considerably underrepresented in the public vocational rehabilitation system, research indicates that rehabilitation counseling professionals should encourage and guide people with MS on how to find out about their situation and do research themselves. Neurologists are a great resource, but they are busy. People with MS need to become proficient at using the Internet to find information and talking to others in an attempt to become more knowledgeable about MS and its symptoms.

Although individuals with MS are significantly underrepresented in the public vocational rehabilitation system, evidence supports its effectiveness at increasing employment outcomes. One way to increase vocational rehabilitation utilization is through dissemination of information. Providers need to be aware of what services are offered and how his/her patients can benefit from them. Upon meeting with a rehabilitation counselor, the counselor's role is to assess the client's health literacy and provide him/her with information and resources to help guide the client's decision-making process.

**Discussion Box**

We have discussed the complexities associated with MS and the challenges related to assisting diagnosed individuals to maintain an active and participatory lifestyle. MS results in physiological, psychological, and emotional difficulties that significantly affect one's ability to interact socially and maintain employment. In rural communities, these sequelae become even more challenging to adequately address. Frequently, there is a lack of both primary care and specialty providers, ancillary professionals (e.g., PT, OT, counseling) are scarce, fewer employment opportunities exist, limited transportation options preclude commuting to adjacent communities for work, and obtaining quality information is difficult. Although there are evidence-based practices available for treating individuals with MS, implementation in rural areas may not be reasonable. Moreover, rehabilitation counselors who cover rural communities encounter extreme geographic barriers that may negatively affect time spent with consumers, and developing relationships with employers across broad distances may prove challenging.

1. Besides the aforementioned challenges, what other concerns does an individual with MS living in a rural area present?
2. In areas with limited employment options, what are some possible solutions that may be feasible?
3. What are possible means of getting MS information to those living in rural areas?

## Health Maintenance Behavior

Health-promoting behaviors, namely, exercise and other physical activity, have been espoused to have a positive impact on improving functional limitations and quality of life (Debolt & McCubbin, 2004). One has little control regarding the course of MS, but physical activity is an area where individuals have significant control, which can substantially alter outcomes. As a result of the sequela (e.g., depression, fatigue) of MS, individuals frequently struggle to continue an active lifestyle and become increasingly isolated, which exacerbate symptoms. Helping individuals understand that physical activity is an evidence-based intervention demonstrated to produce positive outcomes. In fact, in longitudinal research by Stuifbergen, Blozis, Harrison, and Becker (2006), more frequent exercise behaviors among individuals with MS was associated with lower functional limitations and improved quality of life.

Promoting health maintenance behaviors in rural areas fits with the research on rural beliefs about health by allowing individuals to maintain some degree of control of their lives (Weinert & Long, 1987). Part of the rehabilitation counselor's role is to assist clients in understanding the benefits of exercise and to motivate them to take an active role in the management of their illness. Moreover, through an interdisciplinary approach, helping rural individuals with MS to find physical activities that fit within the context of their functional limitations is essential for positive long-term effects.

## MS Health and Symptom Awareness

Although many of the symptoms associated with MS are commonly experienced, having an understanding of which symptoms are MS-related and which are not is often challenging. Self-awareness is viewed as the ability to recognize problems related to impairment (Goverover, Chiaravalloti, Gaudino-Goering, Moore, & DeLuca, 2009). People with MS need to become aware of actions that can be taken to reduce symptoms and to listen to their bodies for signs that rest may be necessary. Furthermore, becoming more self-aware of how MS affects one's body can give individuals a sense of control over appropriate management interventions. It seems reasonable that someone with high self-awareness might recognize symptoms earlier or perhaps experience them as more intense and, therefore, be better equipped to monitor ongoing symptoms and "cope" with them better, experiencing them as less problematic, as compared to someone who is not highly self-aware.

Following one's diagnosis of a chronic medical condition, individuals go through varying stages or phases of acceptance and adjustment. During this time, they begin to pay attention to what changes are taking place in their bodies and typically report them to their providers. Throughout the adjustment phases, individuals will likely benefit from information from professionals that highlights potential changes and symptoms of the illness. In rural communities where specialty providers are scarce, individuals may not have access to complete information about their condition resulting in poor understanding about symptoms and their effects on functioning. Not all clients or patients need help knowing what symptoms to avoid and how best their body works, but many will. For those in need, training on recognizing symptoms and questions to ask their

**Case Study**

Kimberly is a 32-year-old female who was diagnosed with relapsing-remitting MS at the age of 28. Kimberly is unfamiliar with MS and its course and is not sure what symptoms she needs to be concerned with. She has 7 years of experience working as a receptionist at a local business but recently quit her job due to the perceived exacerbations of MS. She has experienced extreme fatigue, depression, and pain. She no longer drives as a result of the pain medication that her family doctor prescribed. She is not currently taking any disease modifying drugs to treat her MS and has relapses every couple of months. She has stopped participating in social activities and feels lonely. She set up a meeting with the office of vocational rehabilitation to discuss her employment options but had to wait nearly 2 months to actually meet with a counselor. Following her meeting, the counselor ascertained that Kimberly's depression and fatigue were the key factors needing to be addressed prior to resuming employment. Additionally, the counselor believed that PT and a neurology consult would be prudent. Kimberly lives about 2 h from the closest major city, which is where the neurologist practices. There are no PTs in her city to help with her mobility.

1. What are some possible options for the rehabilitation counselor to consider to assist Kimberly?
2. What type of job accommodations needs to be considered for Kimberly if she returns to work?
3. Where can the rehabilitation counselor find information to help Kimberly understand her disease course?

health-care professionals can be helpful for shaping their future activities and vocational choices.

## Summary

Multiple sclerosis is a chronic condition that results in substantial changes to one's physiological, psychological, and emotional abilities. Functional challenges are common, which have a detrimental effect on overall perceived quality of life. Although there is no cure for MS, there exist a number of effective disease-modifying drugs along with interventions aimed at improving individuals' participation in important areas of life. Rural areas come with substantial challenges in effectively affording individuals with MS available options for quality care (e.g., lack of providers, unavailable transportation options). Professionals working with individuals in rural communities need to be aware of the numerous challenges and take efforts to ensure that individuals with MS have access to information about their illness, symptoms, and potential activities (e.g., exercise, peer support, social support) that may improve functioning. Considering the paucity of research addressing the potential barriers to care for people with MS in rural communities, additional research is warranted.

### Resources

*National Multiple Sclerosis Society*: http://www.nationalmssociety.org

*WebMD – Multiple Sclerosis*: http://www.webmd.com/multiple-sclerosis/guide/multiple-sclerosis-support-resources

*Overcoming Multiple Sclerosis*: https://overcomingms.org/ms-a-to-z/resources/

*MSLifeLines*: http://www.mslifelines.com/what-is-ms?cmp=M_MS+Core_Misspelling%20MS_Phrase_multiple_sclerosi_Bing_PS&utm_source=google&utm_medium=cpc&utm_campaign=MS%2BCore&utm_content=Misspelling+MS_Phrase&utm_term=multiple+sclerosi

*U.S. Department of Veteran Affairs*: https://www.va.gov/MS/Veterans/resources/index.asp

*PubMed Health*: https://www.ncbi.nlm.nih.gov/pubmedhealth/PMHT0024311/

*AboveMS*: https://www.abovems.com/en_us/home/team/healthcare-team/psychological-support.html?cid=ppc-bng-unbranded-lifestyle-na-41685-unbranded_lifestyle

*MultipleSclerosis.net*: https://multiplesclerosis.net/living-with-ms/dealing-with-ms-diagnosis/

## Learning Exercises

1. Describe the common symptoms associated with MS that affect employment.
2. What are some challenges that need to be addressed along the continuum of seeking employment?
3. What are possible solutions to unavailable transportation?
4. What can rural communities do to attract adequate professionals?

## Field-Based Experiential Assignments

1. Meet with or call a rehabilitation counselor who covers rural communities, and ask about their challenges in providing services to clients.
2. Talk with a specialty provider (e.g., neurologist, PT) to discover what they perceive to be the greatest barriers to employment for individuals with MS.
3. Look up a rural area and develop a list of providers who would be important for an individual with MS.
4. Attend a local MS support group to gain the perspective of the client.

## Multiple Choice Questions

1. How many individuals are estimated to have MS in the worldwide?

   (a) 5 million
   (b) 2.3 million
   (c) 3.2 million
   (d) 1.7 million
2. What is the average age of MS onset?
   (a) 30–40
   (b) 50–60
   (c) 20–30
   (d) No specific age because it varies greatly
3. Which of the following is positively associated with living in a rural community?
   (a) Transportation
   (b) Employment options
   (c) Access to health care
   (d) Social support
4. What is the reported average medication adherence rate for individuals with MS?
   (a) 27%–41%
   (b) 10%–21%
   (c) 45%–60%
   (d) 71%–83%
5. Individuals with MS are _______ in the public vocational rehabilitation system.
   (a) Overrepresented
   (b) Underrepresented
   (c) Normally distributed
   (d) Not typically served due to order of selection
6. Which of the following is *not* a perceived benefit of individual self-management?
   (a) Increased perceived control over illness
   (b) Decrease in hospitalizations
   (c) Increased quality of life
   (d) Improvement in employment outcomes
7. Of the unemployed individuals with MS, what percentage report they would like to return to work?
   (a) 50%
   (b) 75%
   (c) 35%
   (d) 90%
8. MS is the ____________ nontraumatic cause of nervous system disabilities in young adults.
   (a) Second leading
   (b) Third leading
   (c) Leading
   (d) Fourth leading
9. It has been estimated that within 10–15 years of an initial diagnosis of MS, approximately ___________ of patients will experience some degree of impaired mobility.
   (a) 50%
   (b) 25%
   (c) 100%
   (d) 80%
10. What is MSSM?
   (a) Mobility and Social Security Measure
   (b) Multiple Sclerosis Stress Measure
   (c) Multiple Sclerosis Self-Management
   (d) Multiple Social Support Measure

## Key

1. B
2. C
3. D
4. A
5. B
6. D
7. B
8. C
9. D
10. C

## References

Affleck, G., Tennen, H., Pfeiffer, C., & Fifield, J. (1987). Appraisals of control and predictability in adapting to a chronic illness. *Journal of Personality and Social Psychology, 53*, 273–279.

Antao, L., Shaw, L., Ollson, K., Reen, K., To, F., Bossers, A., & Cooper, L. (2013). Chronic pain in episodic illness and its influence on work occupations. *Work, 44*(1), 11–36.

Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W. H. Freeman.

Berger, J. R., Pocoski, J., Preblick, R., & Boklage, S. (2013). Fatigue heralding multiple sclerosis. *Multiple Sclerosis Journal, 19*(11), 1526–1532.

Bishop, M., & Frain, M. (2007). Development and initial analysis of multiple sclerosis self-management scale. *International Journal of MS Care, 9*(2), 35–42.

Bishop, M., & Frain, M. P. (2011). The multiple sclerosis self-management scale: Revision and psychometric analysis. *Rehabilitation Psychology, 56*(2), 150–159.

Bishop, M., Frain, M., & Tschopp, M. K. (2008). Self-management, perceived control, and subjective quality of life in multiple sclerosis: An exploratory study. *Rehabilitation Counseling Bulletin, 51*, 45–56.

Bishop, M., Rumrill, P. D., Jr., & Timblin, R. I. (2016). Medical, psychosocial, and vocational aspects of multiple sclerosis: Implications for rehabilitation professionals. *Journal of Rehabilitation, 82*(2), 6–13.

Bishop, M., Shepard-Jones, K., Roessler, R. T., Rumrill, P. D., Jr., Waletich, B., & Umeasiegbu, V. (2013). Specialized housing needs of Americans with multiple sclerosis: Descriptive results of a national analysis. *Journal of Vocational Rehabilitation, 66*(2), 50–55.

Bosworth, H. (2006). Medication treatment adherence. In H. Bosworth, E. Oddone, & M. Weinberger (Eds.), *Patient treatment adherence: concepts interventions, and measurement*. London: Lawrence Erlbaum Associates.

Browne, P., Chanraratna, D., Tremlett, H., Baker, C., Taylor, B., & Thompson, A. (2014). Atlas of multiple sclerosis 2013: A growing global problem with widespread inequity. *Neurology, 83*, 1022–1024.

Bruce, J. M., Hancock, L. M., Arnett, P., & Lynch, S. (2010). Treatment adherence in multiple sclerosis: Association with emotional status, personality, and cognition. *Journal of Behavioral Medicine, 33*(3), 219–227.

Buchanan, R. J., Wang, S., Martin, R. A., & Ju, H. (2006). Utilization of rehabilitation therapies by nursing home residents with MS at admission. *NeuroRehabilitation, 21*, 223–232.

Buchanan, R., Huang, C., & Crudden, A. (2012). Use of the internet by informal caregivers assisting people with multiple sclerosis. *Journal of Technology in Human Services, 30*, 72–93.

Bycroft, J., & Tracey, J. (2006). Self-management support: A win–win solution for the 21st century. *New Zealand Family Physician, 33*, 243–248.

Carver, C. S., Harris, S. D., Lehman, J. M., Durel, L. A., Antoni, M. H., Spencer, S. M., & Pozo-Kaderman, C. (2000). How important is the perception of personal control? Studies of early stage breast cancer patients. *Personality and Social Psychology Bulletin, 26*(2), 139–149.

Chiu, C. Y., Chan, F., Bishop, M., da Silva Cardoso, E., & O'Neill, J. (2013). State vocational rehabilitation services and employment in multiple sclerosis. *Multiple Sclerosis Journal, 19*(12), 1655–1664.

Cochran, J., & Conn, V. S. (2008). Meta-analysis of quality of life outcomes following diabetes self-management training. *Diabetes Educator, 34*, 815–823.

Davis, P., & Tyry, T. (2008). NARCOMS Report-2007 Registry Update. *Multiple Sclerosis Quarterly Report, 26* (4). Retrieved from http://www.unitedspinal.org/publications/msqr/2008/02/04/narcoms-report-2007-registry-update/

Debolt, L. S., & McCubbin, J. A. (2004). The effects of home-based resistance exercise on balance, power, and mobility in adults with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation, 85*, 290–297.

Devins, G. M., & Shnek, Z. M. (2000). Multiple sclerosis. In R. G. Frank & T. R. Elliott (Eds.), *Handbook of rehabilitation psychology* (pp. 163–184). Washington, DC: American Psychological Association.

Easter Seals Disability Services and National Alliance for Caregiving. (2006). *Caregiving in rural America*. Retrieved from http://es.easterseals.com/site/DocServer/Caregiving-in-Rural_Saveas_Compress.pdf?docID=49463

Endler, N. S., Kocovski, N. L., & Macrodimitris, S. D. (2001). Coping, efficacy, and perceived control in acute versus chronic illness. *Personal and Individual Differences, 30*, 617–625.

Foster, G., Taylor, S. J., Eldridge, S. E., Ramsay, J., & Griffiths, C. J. (2007). Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database of Systematic Reviews,* (4), CD005108.

Fraser, R. T., Kraft, G. H., Ehde, D. M., & Johnson, K. L. (2006). *The MS workbook: Living fully with multiple sclerosis*. Oakland, CA: New Harbinger Publications, Inc..

Galushko, M., Golla, H., Strupp, J., Karbach, U., Kaiser, C., Ernstmann, N., Pfaff, H., Ostgathe, C., & Voltz, R. (2014). Unmet needs of patients feeling severely affected by multiple sclerosis in Germany: A qualitative study. *Journal of Palliative Medicine*, 17(3), 274–281.

Golla, A.M., Malhotra, A., Nanda, P., & Mehra, R. (2011). *Understanding and measuring women's economic empowerment. Definition, framework and indicators*. Washington, DC: ICRW (International Center for Research on Women).

Gottberg, K., Einarsson, U., Ytterberg, C., Fredrikson, S., von Koch, L., & Holmqvist, L. W. (2008). Use of health care services and satisfaction with care in people with multiple sclerosis in Stockholm County: A population-based study. *Multiple Sclerosis, 14*, 962–971. doi: 10.1177/1352458508089688

Goverover, Y., Chiaravalloti, N., Gaudino-Goering, E., Moore, N., & DeLuca, J. (2009). The relationship among performance of instrumental activities of daily living, self-report of quality of life, and self-awareness of functional status in individuals with multiple sclerosis. *Rehabilitation Psychology, 54*(1), 60.

Halper, J. (2007). The psychosocial effect of multiple sclerosis: The impact of relapses. *Journal of Neurological Sciences, 256*, S34–S38.

Kennedy, A. P., Reeves, D., Bower, P. J., Lee, V., Middleton, E., Richardson, G., & Rogers, A. E. (2007). The effectiveness and cost effectiveness of a national lay-led self-care support programme for patients with long-term conditions: A pragmatic randomised controlled trial. *Journal of Epidemiology and Community Health, 61*, 254–261.

Krokavcova, M., van Dijk, J. P., Nagyova, I., Rosenberger, J., Gavelova, M., Middel, B., … Groothoff, J. W. (2008). Social support as a predictor of perceived health status in patients with multiple sclerosis. *Patient Education and Counseling, 73*(1), 159–165.

Labiano-Fontcuberta, A., Mitchell, A. J., Moreno-García, S., & Benito-León, J. (2014). Cognitive impairment in patients with multiple sclerosis predicts worse caregiver's health-related quality of life. *Multiple Sclerosis Journal, 20*(13), 1769–1779.

Lorig, K. (1993). Self-management of chronic illness: A model for the future (self-care and older adults). *Generations, 17*(3), 11–14.

Lorig, K. R., & Holman, H. R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26*, 1–7.

Lorig, K. R., Ritter, P. L., Laurent, D. D., & Plant, K. (2006). Internet-based chronic disease self-management: A randomized trial. *Medical Care, 44*, 964–971.

Mackert, M., Ball, J., & Lopez, N. (2011). Health literacy awareness training for healthcare workers: Improving knowledge and intentions to use clear communication techniques. *Patient Education and Counseling, 85*(3), e225–e228.

McReynolds, C., & Koch, L. (2001). Psychological issues. In P. D. Rumrill Jr. & M. Hennesey (Eds.), *Multiple sclerosis: A guide for rehabilitation and health care professionals* (pp. 44–78). Springfield, IL: Charles C. Thomas.

Moore, P., Hirst, C., Harding, K. E., Clarkson, H., Pickersgill, T. P., & Robertson, N. P. (2012). Multiple sclerosis relapses and depression. *Journal of Psychosomatic Research, 73*, 272–276.

Myhr, K.M. (2008). Diagnosis and treatment of multiple sclerosis. *Acta Neurologica Scandinavica, 117*, 12–21. doi: 10.1111/j.1600-0404.2008.01026

National Multiple Sclerosis Society. (2015). *Estimating the prevalence of MS*. Retrieved from http://www.nationalmssociety.org/About-the-Society/MS-Prevalence

Polman, C., Thompson, A., Murray, T., Bowling, A., & Noseworthy, J. (2006). *Multiple sclerosis: The guide to treatment and management*. New York, NY: Demos Medical.

Pohar, S., Jones, C., Warren, S., & Turpin. (2007). Health status and health care utilization of multiple sclerosis in Canada. *Canadian Journal of Neurological Sciences*, 34, 167–174. https://doi.org/10.1017/S0317167100005990

Pugliatti, M., Rosati, G., Carton, H., Riise, T., Drulovic, J., Ve` Csei, L., & Milanov, I. (2006). The epidemiology of multiple sclerosis in Europe. *Eur J Neurol*, 13, 700–722.

Roessler, R. T., Neath, J., McMahon, B. T., & Rumrill, P. D. (2007). Workplace discrimination outcomes and their predictive factors for adults with multiple sclerosis. *Rehabilitation Counseling Bulletin, 50*(3), 139–152.

Rumrill, P. D. (2006). Help to stay at work: Vocational rehabilitation strategies for people with multiple sclerosis. *Multiple Sclerosis in Focus, 7*, 14–18.

Schillinger, D., Bindman, A., Wang, F., Stewart, A., & Piette, J. (2004). Functional health literacy and the quality of physician–patient communication among diabetes patients. *Patient Education and Counseling, 52*(3), 315–323.

Souza, A., Kelleher, A., Cooper, R., Cooper, R. A., Iezzoni, L. I., & Collins, D. M. (2010). Multiple sclerosis and mobility-related assistive technology: Systematic review of literature. *Journal of Rehabilitation Research and Development, 47*(3), 213–224.

Stein, H. (1982). The annual cycle and the cultural nexus of health care behavior among Oklahoma wheat farming families. *Cultural Medicine and Psychiatry, 6*, 81–89.

Stein, H., & Pontious, J. (1985). The family and beyond. The larger context of noncompliance. *Family Systems Medicine, 3*, 179.

Stuifbergen, A. K., Blozis, S. A., Harrison, T. C., & Becker, H. A. (2006). Exercise, functional limitations, and quality of life: A longitudinal study of persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation, 87*(7), 935–943.

Thompson, S. (2002). The role of personal control in adaptive functioning. In C. R. Snyder & S. J. Lopez (Eds.), *Handbook of positive psychology* (pp. 202–213). Oxford, UK: Oxford University Press.

Turner, A. P., Williams, R. M., Sloan, A. P., & Haselkorn, J. K. (2009). Injection anxiety remains a long-term barrier to medication adherence in multiple sclerosis. *Rehabilitation Psychology, 54*, 116–121.

Weinert, C., & Long, K. (1987). Understanding the health care needs of rural families. *Family Relations, 36*, 450–455.

Wilper, A. P., Woolhandler, S., Lasser, K. E., McCormick, D., Bor, D. H., & Himmelstein, D. U. (2008). A national study of chronic disease prevalence and access to care in uninsured US adults. *Annals of Internal Medicine, 149*, 170–176.

Winters, C., Cudney, S., Sullivan, T., & Thuesen, A. (2006). The rural context and women's self-management of chronic health conditions. *Chronic Illness, 2*, 273–289.

World Health Organization (WHO). (2003). *Adherence to long-term therapies: Evidence for action.* Geneva, Switzerland: WHO.