

Article 23

Multiple Sclerosis: Moving Beyond Physical and Neurological Implications Into Family Counseling

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Abstract

Multiple sclerosis (MS) is a chronic, unpredictable central nervous system disorder characterized by an attack against the central nervous system (brain, spinal cord, and optic nerves). Variations in physical, cognitive, and psychological symptoms, including the potential presence of numbness or tingling, memory loss, depression, and even sexual dysfunction, require family counselors to become familiar with the medical aspects of MS, possible symptoms, and the necessary steps for an individual to receive appropriate psychological treatment. An overview of the medical aspects of MS, gender and cultural factors, prognosis, and individual, couple, and family dynamics, as well as treatment considerations of MS, are presented. An illustrative case study is provided.

Keywords: Multiple sclerosis, family dynamics, individual dynamics, illness perception, couples counseling, neurological

Multiple Sclerosis (MS) is a chronic, individualized, and often unpredictable disease that attacks an individual's central nervous system. Although the origin of MS is unknown, researchers to date point to a potential variety of causes, making prevention and even treatment difficult. The National Multiple Sclerosis Society (n.d.) established that research should concentrate on fields of immunology, environment, genetics, and infection as possible areas which may shed light on an individual's risk of developing

MS. The uncertainty of potential causes is further complicated by variation in reported symptoms as well as the potential for signs to disappear and even reappear. Furthermore, no singular test allows for the diagnosis of MS, leading to the need for multiple procedures over a period of time to rule out all other diagnoses prior to an individual being provided an MS diagnosis.

Variations in physical, cognitive, and psychological symptoms, including the potential presence of numbness or tingling, memory loss, depression, and even sexual dysfunction, require family counselors to become knowledgeable of the medical aspects of MS, including possible symptoms and the necessary steps at which an individual should receive appropriate testing. The current article provides an overview of the medical aspects of MS, gender and cultural factors, prognosis, individual, couple, and family dynamics, as well as treatment considerations of MS. A case illustration is presented with the goal to equip family counselors with the knowledge to provide services to an individual and family dealing with the effects of this disease.

Medical Aspects of Multiple Sclerosis

MS, thought to be an autoimmune disorder, involves an attack against the central nervous system, including the brain, spinal cord, and optic nerve (University of Maryland Medical Center, 2011). The myelin, which is the fatty substance that surrounds and insulates the nerve fibers and allows a nerve to transmit signals rapidly, is damaged resulting in demyelination. Demyelination results in several hard, scarred tissues referred to as lesions or plaques. MS also causes damage to axons that carry electric impulses away from the neuron's cell body and transmits information to other neurons, muscles, or glands. The severity of the demyelination, as well as the location of the plaques, increases the symptoms and severity of the disease. The disease is progressive and worsens over time (Andrew & Andrew, 2012).

Because physicians are not required to report new cases of MS to the Center for Disease Control (CDC), it is hard to know the incidence (i.e., people diagnosed every year) or the prevalence (i.e., how many people have MS at any one time) within the United States (National MS Society, 2013). However, according to the National Institute of Neurological Disorders and Stroke (NINDS, 2013), MS affects approximately 400,000 Americans, and 2.5 million people are affected worldwide.

MS is grouped into four major disease categories (National MS Society, 2013). The first and most common category is relapsing-remitting multiple sclerosis (RRMS), which is characterized by flare-ups often referred to as relapses and exacerbations. Approximately 85% of people are first diagnosed with RRMS (National MS Society, 2013). Exacerbations are caused by inflammation of the central nervous system. The inflammation causes damage to the myelin and blocks transmission of nerve impulses. The episode can last from a few days to several weeks and even months. The flare-ups are followed by recovery periods in which there is no disease progression (University of Maryland Medical Center, 2011). Some people with RRMS will develop the second category called secondary-progressive multiple sclerosis (SPMS) in which the disease worsens steadily with minor remissions. Approximately 10% of people are diagnosed with the third type of MS known as primary-progressive multiple sclerosis (PPMS) in which the disease slowly worsens from the beginning, and there are no relapses or

remissions. This type of MS is most resistant to medications (University of Maryland Medical Center, 2011). The fourth and final type of MS, progressive-relapsing multiple sclerosis (PRMS) is the rarest of the four, and less than 5% of people are diagnosed with PRMS. According to the University of Maryland Medical Center (2011), “It is progressive from the start with intermittent flare-ups of worsening symptoms along the way. There are no periods of remission” (para. 4).

The severity of the disease varies among patients, and the disease may be mild, moderate, or severe. Although the majority of people are diagnosed between the ages of 20 and 50, individuals as young as 2 have been diagnosed (National Multiple Sclerosis Society, 2013). The majority of patients have the first category of MS, relapsing-remitting MS, with exacerbations (attacks, relapses, or flare ups) followed by periods of remission. According to the NINDS (2013), initial symptoms of MS include vision problems such as blurred or double vision, color distortion, and in some cases blindness in one eye. Additional symptoms caused by MS include fatigue, loss of balance, poor coordination, difficulty walking, muscle weakness, spasms, slurred speech, tremors, numbness, and bladder and bowel problems (University of Maryland Medical Center, 2011). Researchers estimate that half of all patients experience problems with memory, attention, and concentration (NINDS, 2013). In the worst case, MS can cause complete paralysis. Symptoms may come and go over time with the person regaining all lost functions. However, others may experience symptoms on a permanent basis such as difficulty with speech and vision. Depression is common among MS patients (NINDS, 2013), and suicide rates are higher than average (University of Maryland Medical Center, 2011).

MS is a complex disease, and like other autoimmune disorders, the exact cause is unknown. It is likely that a combination of environmental and genetic factors work together to cause MS. Although MS is not hereditary, researchers suggest that genetic factors may be involved in determining an individual’s susceptibility to the disease (University of Maryland Medical Center, 2011). The National MS Society (2013) reported the risk of developing MS is 1/750 for the general population. However, the risk increases to 1/40 for people who have close relatives diagnosed with MS.

Gender and Cultural Factors

Similar to other medical conditions, there are gender and cultural factors that need to be considered with MS. Due to the complex relationship among genetics, environment, and sex hormones, approximately two to three times more women have MS than men (Bove et al., 2013). Women, but not men, who begin puberty at an earlier age are at increased risk to develop MS (Ramagopalan et al., 2009). Gender and age also interact to create differences in MS symptoms and severity throughout the lifespan. Among individuals who have a late onset of MS (i.e., after 50 years of age), women appear to have increased coordination problems when compared with men. However, researchers have found that men have more motor symptoms (Bove et al., 2012).

Geographic location has also appeared to have a relationship with MS diagnosis. According to the National MS Society (2008), “MS also occurs more frequently in people with Northern European ancestry” (p. 68). Several researchers investigated the prevalence of MS in European countries, as well as the relationship between latitude (i.e., geographic location) and MS incidence. Ahlgren, Oden, and Lycke et al. (2011)

examined the number of individuals diagnosed with MS. These researchers found that the potential for MS increased with northern latitude for men and women. Simpson, Blizzard, Otahal, Van der Mei, and Taylor (2011) found similar findings and concluded that there is a positive relationship between latitude and MS prevalence. The aforementioned information highlights the complex interplay among genetic, geographic, and environmental factors that influences MS symptoms and presenting concerns in men and women.

Although Caucasian Americans have higher reported rates of MS (University of Maryland Medical Center, 2011), African Americans experience a more severe disease course than Caucasian Americans. Naismith, Trinkaus, and Cross (2006) highlighted that African Americans with MS had higher incidents of cerebellar dysfunction and rapid accumulation of disabilities. African Americans with MS also required assistive devices earlier than Caucasian Americans. This is likely due to genetic differences and/or environmental factors (Johnson et al., 2010). It is worth noting that the specific phase of MS interacts with cultural factors to influence presenting concerns and symptoms. For example, Johnson, Terrell, Sargent, and Kaufman (2007) did not uncover differences in symptom severity between African Americans and Caucasian Americans in later phases of MS. However, Kaufman, Johnson, Moyer, Bivens, and Norton (2003) previously found that compared with White individuals, African Americans were more likely to experience pyramidal system involvement and greater disability in early stages of MS.

Prognosis

At present, there is no cure for MS, and there is considerable variability in degree of progression and disability from client to client. Individuals with multiple sclerosis, on average, live for 25 years following diagnosis (Andrew & Andrew, 2012). According to Scalfari et al. (2010), the majority of people with MS do not become severely disabled with less than 5% diagnosed having a severe disability within 5 years. However, only 10-20% experience few or no symptoms without therapy over 20 years.

Medical doctors use the Expanded Disability Status Scale (EDSS) to evaluate disease progression and measure the physical disability. The scale ranges from 0 (normal neurologic examination) to 10 (death due to MS) in half-point increments. For example, an EDSS score of 4 is defined as limited walking but without an aid, a score of 6 is walking with unilateral aid, and a score of 7 means an individual requires a wheelchair. In a 30 year longitudinal study, Confavreux and Vukusic (2006) found the median age ($n=1,844$ participants) to reach a score of 4 was 44 years, score of 6 was 55 years, and a score of 7 was 63 years. Kremenchutzky, Rice, Baskerville, Wingerchuk, and Ebers (2006) found similar results following 505 patients for 25 years with a mean age of patients reaching an EDSS score of 4 as 40 years. Erbers, Travoulsee, and Li (2010) found the median time from disease onset to needing a walking aid of 18 years was likely a result of the number of relapses in the early phase of the disease. The median time from onset to use of a walking aid was 20 years for those who had one relapse within the first two years, and a median time of 10 years for those that had three or more relapses within the initial period.

Although there is no cure for MS, a comprehensive treatment approach to modifying the disease course (i.e., disease modifying drugs), treating the exacerbations (i.e., relapses, flare ups), effectively managing MS symptoms (i.e., medication and

rehabilitation services), and providing psychological support is recommended. Rehabilitation strategies such as physical therapy, occupational therapy, therapy for speech, cognitive rehabilitation, and vocational rehabilitation can help MS clients maintain their ability at home and work.

Individual Dynamics in MS

According to Andrew and Andrew (2012), “Multiple sclerosis affects the nerves in the brain and spinal cord and the symptoms are many and varied” (p. 108). The uncertainty of risk factors and unpredictability of symptoms result in a substantially individualized experience for all individuals diagnosed with MS. The severity and course for individuals with MS is substantially linked to specific limitations. Although Andrew and Andrew (2012) acknowledged that MS could be fatal in the initial 12 months, most individuals will live at least 25 years after diagnosis. Unfortunately, there is no way to know which of the two possibilities will occur with any one individual.

Although common symptoms vary, the most common symptoms often involve the motor nerves (e.g., tremors, poor coordination), sensory nerves (e.g., numbness), cranial nerves (e.g., impaired balance, dizziness), autonomic nerves (e.g., bladder control, sexual impotence), and the brain (e.g., cognitive dysfunction, emotional lability) among others (Andrew & Andrew, 2012). Although individuals may experience all or none of the aforementioned issues, weather appears to be a consistent factor with cool temperatures associated with optimal functioning. Limitations associated with these symptoms are also likely to impact vocational abilities with individuals employed in areas that require physical activities more affected (Batisti, 2013). Because there is no cure or effective treatment for MS, vocational issues are likely to occur at some point in the progression of the disease.

Whereas physical limitations often provide a visual establishment of MS, Chwastiak and Ehde (2007) noted that the most significant symptoms are often psychological in nature. In fact, the authors concluded that as many as one out of seven deaths of individuals diagnosed with MS could be attributed to suicide, while rates of anxiety and depression were noted as higher than the general population. Presence of these psychological symptoms has potential to further complicate the limitations faced by individuals with MS. In fact, risks of social isolation and substance abuse are increased within this population (Chwastiak & Ehde, 2007). Understanding the potential complications of these risks, as well as components associated with increased therapeutic compliance, is instrumental in providing effective therapeutic treatment.

Illness Representation

Illness representations refer to an individual’s perceptions of the (a) cause of an illness, (b) consequences of an illness, (c) personal control over the illness, and (d) length of the illness (Sperry, 2011b). Among individuals with MS, illness representations might be related to health-related quality of life, high life satisfaction, low depression, and low anxiety (Chalk, 2007). The most important clinical consideration is that clinicians can work with MS clients to modify beliefs about their illness.

Spain, Tubridy, Kilpatrick, Adams, and Holmes (2007) identified illness perceptions of MS clients using a categorical regression analysis. Noteworthy was that

illness perceptions had an independent effect on health-related quality of life. The implication of this finding is that clinicians can use interventions to help MS clients improve illness perceptions. Another study by Chalk (2007) addressed cognitive and behavioral factors related to psychological adjustment among MS clients. Both problem solving and acceptance coping were related to positive outcomes. It is worth noting that, “MS patients’ level of physical disability was not significantly related to psychological adjustment” (p. 563). The implication of this finding is that clinicians can teach clients effective coping responses to modify illness representations (Chalk, 2007).

Couple and Family Dynamics in MS

Although medical issues associated with MS are largely targeted in medical journals (e.g., Wilkinson & das Nair, 2013), Sperry (2011a) cautioned that biomedical formulations of cases fail to address psychological, social, and cultural aspects associated with the presence of the disease. Therefore, counselors must be knowledgeable about the potential impact that an MS diagnosis may have on relationships, including larger family systems. For example, McPheters and Sandberg (2010) found that stronger, more stable relationships within couples were associated with reduced stress among patients diagnosed with MS and their partners. As such, counselors must address other factors which may be the source of relationship difficulties.

Hassan-Smith and Douglas (2011) noted that although no cure exists for MS, advances in treatment attempt to reduce symptoms associated with disease progression. Despite these treatments, presence of common symptoms may impact couple and family dynamics. In fact, Hassan-Smith and Douglas (2011) highlighted the potential for an individual diagnosed with MS, especially men, to experience sexual dysfunction. Coupled with the potential for having a significant socioeconomic impact (Andrew & Andrew, 2012), the presence of MS symptoms has potential to increase stress within the family system.

Individual, Couple, and Family Treatment Considerations in MS

Counselors working with families dealing with the onset of a medical diagnosis such as MS should conceptualize the case based on a biopsychosocial model of understanding (Sperry, 2013). According to Sperry, case conceptualization, which serves as a fundamental component of treatment, must include (a) a diagnostic formulation or description of the presenting problem, (b) a clinical formulation explaining the “why,” (c) a cultural formulation describing the impact of specific cultural characteristics relative to the presenting problem, and (d) a treatment formulation or roadmap based on information obtained from the other three formulations. As such, case conceptualization needs to address the impact of MS symptoms and resultant effects on family systems.

Although no study was found to date that focused on family treatment associated with individuals diagnosed with MS, Sperry (2009) noted a fundamental intervention in working with individuals diagnosed with chronic medical conditions is the need to increase the client’s education on the disease in order to dispel misconceptions that may exist. Understanding the client or family’s perception of the disease will help develop treatment approaches in which the client will demonstrate compliance. In addition to targeting perceptions associated with a diagnosis, Sperry (2013) asserted that a

therapeutic plan should address individual factors of the client, including relative strengths, weaknesses, and resources; representations of the family structure including interaction patterns; cultural factors including factors related to all members of the family; and narrative and social discourses or totality of the client's story. Utilizing these recommendations, the following case example exemplifies a potential way for a counselor to address presenting concerns among members of a family where a MS diagnosis exists.

Case Illustration

Warren (31) and Lynn (30) have been married for 7 years and have two young children, Nicholas (6) and Ryan (5). Warren and Lynn met shortly after high school, but made the decision to wait for marriage and children until Warren was able to get established in his field of construction. For the past 13 years, Warren has worked his way up through a small, privately owned company. After 5 years of working first as a construction apprentice and eventually as a construction worker, Warren was promoted to the position of foreman. Following the substantial raise in pay, Warren and Lynn decided to marry and start a family. The two bought a small piece of land from Warren's employer, and eventually, Warren built the family home from the ground up. Soon, thereafter, Warren and Lynn were joined by a son, Nicholas, and daughter, Ryan. With Warren's six figure salary, Lynn was able to stay home to support the family, while Warren worked.

Although the birth of Ryan marked a joyous occasion for the family, the life event also corresponded to the onset of the presence of physical concerns for Warren. At first, Warren began experiencing some numbness and tingling in his arms and feet, which he quickly associated with the potential presence of a pinched nerve. After the persistence of these symptoms for several months, Warren soon recognized increasing difficulties with balance and memory. Thinking that the symptoms were the product of being overworked, Warren continued to ignore his concerns about the symptoms. One day, Warren was at work when he tripped and was knocked out. Because he was the only one at the project at the time, he said nothing. When he returned home that day, however, he spoke to his wife who, too, had mounting concerns about his physical symptoms. At her urging, he sought advice from his primary care physician.

Following a series of medical procedures and months of testing, Warren's physician referred him to a neurologist who diagnosed him with MS. Since this time nearly four years ago, Warren has recognized what has appeared to be a progression of symptoms. Ultimately, he was forced to step down from his position as a foreman to a much less physically demanding position of carpenter assistant. The reduction in position was accompanied by a significant reduction in pay, resulting in the need for Lynn to seek employment in order for the family to meet their financial obligations. Too proud to inform his co-workers of his MS diagnosis, Warren's issues at work began to intensify. Although he became physically unable to complete some tasks necessary to his position due to MS symptoms, Warren resolved that it would be better to let his co-workers believe that his lack of performance was due to being lazy as opposed to letting them know he had MS. Convinced that the diagnosis and symptoms are beyond his control, Warren has grown increasingly depressed. In addition to the increasing work related

issues, Warren's problems began spilling over into the home. Believing that his role as male and provider were gone, he began to establish his roles in other areas. In fact, Warren displayed numerous transgressions as he stepped outside of his marriage, having numerous affairs. When Lynn threatened to leave the marriage and take the children with her, Warren agreed to seek out family therapy.

Although Warren and Lynn enter counseling with the fundamental goal of saving their relationship and family, they soon reveal that the religious beliefs of Lynn's family surrounding the sanctity of marriage and Warren's transgressions have further complicated the dynamics as Lynn's family refuses to support her unless she leaves Warren. During the intake and subsequent follow up session, it became evident that Warren's behaviors are a direct result of his inability to come to terms with his diagnosis, the uncertainty of his future, and his loss of identity as a result of his physical limitations. As such, Warren was provided a diagnosis of Adjustment Disorder with Mixed Disturbance of Emotions and Conduct.

Utilizing family systems therapy, the counselor recognizes that interactions among family members and the reversal of roles in the family as a result of Warren's limitations are connected. The decrease in Warren's pay coupled with Lynn's return to work ultimately resulted in Warren losing the role of primary provider for the family. Although Lynn's motherly instinct caused her to seek employment to maintain the family's home, she failed to recognize the implications of the role reversal. Instead, she views Warren's maladaptive coping mechanisms as a reflection of the couple's relationship. In reaction, Lynn's parents side with this assessment and attempt to renegotiate their roles in the overarching family system. Readjustment of roles without effective communication is likely to increase hostility and conflict.

Given the dynamics at play, three specific goals were developed in family therapy. The preliminary goal was set to increase the participants' knowledge and awareness of Warren's MS diagnosis, including the potential courses of progression and courses of treatment. Understanding available resources that may support Warren in maintaining a sense of accomplishment and meaning, such as services through vocational rehabilitation, might be beneficial in supporting Warren to develop realistic employment expectations. Individual and family sessions were also dedicated to help Warren process his illness perceptions, increase acceptance of his illness, and understand the consequences of his illness. In addition to an established goal of developing a realistic understanding of prognosis and abilities, the participants set a goal to renegotiate family roles within the context of developing roles and responsibilities which are realistic and with which participants can agree. Establishing fulfilling roles, rules, and responsibilities is necessary to develop family functioning which provides individual members with a sense of accomplishment and meaning. Finally, a goal was set to enhance the family's use of coping skills to deal with the stresses associated with the unpredictable course of the disease. Developing interventions focused on establishing effective coping skills provides an opportunity for both Warren and his family to problem solve around challenges faced as a result of the disease.

Implications for the Counseling Profession

As demonstrated in the case illustration, medical conditions have the potential to impact not only the individual but also larger systems, including couples and families. The American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5)* identifies this potential by establishing a “due to another medical condition” specifier with several diagnoses. When working with individuals with medical conditions, it is important for the counselor to understand the potential impacts of those conditions on the mental health of the client and the condition of the family. Just as counselors would use psychoeducation to provide clients with a better understanding of their mental health condition, it is important that they also provide clients with a clear and accurate understanding of their physical health conditions and the potential impact of those conditions on quality of living (Sperry, 2013). Given the unpredictability of multiple sclerosis’s progression and the lack of an established cure, counselors must prepare clients for various outcomes.

Concluding Notes

MS is a chronic and individualized disease that can impact individual clients and their families. Similar to other chronic medical conditions, MS has significant physical, cognitive, and psychological symptoms that need to be included in a psychosocial counseling approach. Family and individual therapists can become knowledgeable of presenting concerns associated with MS and learn clinical skills to help this population. The case example highlights how a family therapist can help clients with MS process illness perceptions, develop positive coping responses, and improve their understanding of family roles.

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