FACTORS AFFECTING QUALITY

OF LIFE IN PERSONS WITH

MULTIPLE SCLEROSIS

by

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Abstract

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Multiple sclerosis is an autoimmune disease that can negatively affect the physical, emotional, and social aspects of one's life. This purpose of this descriptive-correlational study was to explore the relationships among individual characteristics, perceived healthcare provider engagement, treatment adherence, functional ability, and quality of life in persons with multiple sclerosis (MS). Additionally, differences in perceived healthcare provider engagement, treatment adherence, functional ability, and quality of life were examined across the four MS disease stages of relapsing-remitting, secondary-progressive, primary-progressive, and progressive-relapsing. A convenience sample of individuals ($N =$ 158) with MS completed an online survey related to perceived healthcare provider engagement, treatment adherence, functional ability, and quality of life. Moderate correlations were found between perceived healthcare provider engagement and treatment adherence ($r = .389, p < .000$) along with perceived healthcare provider engagement and quality of life ($r = .355, p < .000$). A strong correlation was found between treatment adherence and quality of life ($r = .437, p < .000$) and a weak correlation between functional ability and quality of life ($r = .218, p = .001$). Additionally, significant group differences were found related to functional ability across MS disease stages, $\chi^2 (2, n = 147) = 6.92, p < 0.001$. Post hoc analysis revealed a difference between individuals with relapsing-remitting status ($M = 9.19, SD = 1.16$) and secondary-progressive status ($M = 7.06, SD = 2.75$) on functional ability, $U = 444, p < .000$. The results of this study provide the basis for future research using experimental designs to examine specific factors affecting quality of life among those with MS.

Table of Contents

List of Figures

List of Tables

Chapter 1

Introduction

Multiple sclerosis (MS) is a debilitating disease that often permeates every aspect of a person's life. Persons with MS experience significant hardships throughout the lifespan that can greatly affect their overall quality of life (QoL). Disease progression, adaptation, and social connectedness interact with other factors such as physical disability to determine QoL in this population. Factors associated with MS such as physical limitations, social isolation, and cognitive alterations can serve as barriers to improving QoL (Fernández, Baumstarck-Barrau, Simeoni, & Auquier, 2011). Individuals with MS experience depression, loss of normal bowel and bladder function, significant fatigue, high unemployment rates, relationship difficulties, and limited access to specialized healthcare. Other determinants of QoL such as provider engagement, treatment adherence, and functional ability among persons with MS may be more amenable to nurse interventions (Gurwell & Berger, 2012). The relationships among these determinants were not known and served as the focus of the proposed study. This chapter includes an introduction to MS along with its background and significance, and a discussion of the theoretical framework for the study.

Statement of the Problem and Research Questions

MS is a complex disease that creates a constellation of factors that can alter an individual's life. Burdened with physical dysfunction, psychological stressors, and social isolation, individuals with MS are considered a vulnerable population that experiences a lower quality of life (McCabe, Stokes, & McDonald, 2009; Józef A. Opara, Jaracz, & Brola, 2010). Additionally, individuals with MS experience discrimination, negative socioeconomic consequences, and poor access to speci1alty services (Buchanan et al., 2010; Roessler, Hennessey, Neath, Rumrill, & Nissen, 2011). Living with MS requires a person to dispatch a variety of adaptation and coping strategies to maintain an overall level of wellbeing (Irvine, Davidson, Hoy, & Lowe-Strong, 2009; McCabe et al., 2009). Because of this increased burden, understanding factors that influence QoL becomes increasingly important in order to assist those with MS to lead meaningful lives (Hwang, Cvitanovich, Doroski, & Vajarakitipongse, 2011). Moreover, increased knowledge related to QoL can lead to improved healthcare provider interactions, increased treatment adherence, and overall health status (Forbes, While, & Taylor, 2007).

1

No single study has focused on the interrelatedness of healthcare provider engagement, treatment adherence, functional ability, and QoL among persons with MS. The purpose of this study was to examine the relationships among patient characteristics, healthcare provider engagement, treatment adherence, functional ability, and QoL among individuals with MS in order to gain a greater understanding of their interactions. The research questions for this study were:

1. What are the relationships among patient characteristics, healthcare provider engagement, treatment adherence, functional ability, and QoL in persons with multiple sclerosis?

2. What are the differences in perceived healthcare provider engagement, treatment adherence, functional ability, and quality of life across the four MS disease stages of relapsing-remitting, secondary-progressive, primary-progressive, and progressive-relapsing?

Background

Multiple Sclerosis Defined

MS is a chronic inflammatory disease primarily affecting the brain and spinal cord (Brodkey, Ben-Zacharia, & Reardon, 2011). The disease disrupts electrical impulses within the brain and spinal cord by destroying the fatty tissue surrounding the cells. The progression of MS is highly variable and unpredictable with age related symptoms (Buchanan et al., 2009). People with MS can experience neurological deficits, increasing disability, and medical decline over the course of 30 years (Buchanan, Huang, & Chakravorty, 2011). Fatigue and depression usually present early following diagnosis while functional disability and cognitive decline appear later in the disease course. Four distinct patterns are associated with the disease course of MS that include relapsing-remitting, secondary-progressive, primary progressive, and progressive relapsing.

Relapsing-remitting is a pattern distinguished by acute attacks that often resolve to near complete recovery with no disease progression between attacks (Brodkey et al., 2011). Secondary-progressive is characterized by symptom progression at variable rates. Primary-progressive is distinguished by a continuous worsening of neurological symptoms without remission. Progressive-relapsing MS is characterized by acute exacerbations without recovery (Brodkey et al., 2011).

Treatment Regimens for MS

MS is an unpredictable disease that affects each person differently. Treatment regimens focus on managing symptoms and modifying the disease course. The symptoms associated with MS are classified into primary, secondary and tertiary. Common primary symptoms include optic neuritis, spasticity, fatigue, clinical depression, bowel and bladder dysfunction, and short-term memory loss. Secondary symptoms include contractures, immobility, dysphasia, and respiratory changes. Tertiary symptoms include mood disorders such as anxiety and depression (Brodkey et al., 2011).

During periods of disease exacerbation, corticosteroids are used to decrease the amount of inflammation in the central nervous system. The usefulness of long-term steroids and MS, however, is poorly understood. Many individuals with comorbidities such as hypertension or diabetes mellitus can experience more severe long-term effects by taking corticosteroids (Brodkey et al., 2011).

Disease modifying therapies such as beta interferons reduce inflammation with the purpose of slowing relapse rates and disease progression (Brodkey et al., 2011; Rosenzweig, Hartman, & MacKenzie, 2010). Although this form of treatment has been shown to decrease the amount of inflammatory lesions by up to 80%, significant adverse effects may occur (Coppola et al. 2006). Flu-like symptoms, anemia, thrombocytopenia, headache, and depression are among the most common adverse effects. Disease modifying therapies are most often taken in the form of a subcutaneous injection with many individuals commonly reporting injection site irritation. The adverse side effects associated with disease modifying therapies can greatly affect adherence to therapy among individuals with MS (Brodkey et al., 2011).

An unpredictable disease course along with physical and cognitive impairment may create unique challenges related to treatment adherence. Previous studies report discontinuation of disease modifying treatments from 20% to 50% in the first two years (Klauer & Zettl, 2008a). Caon et al. (2010) reviewed barriers to treatment adherence among individuals with MS. Common barriers included difficulties with self-injection, medication side effects, and level of trust with their healthcare provider. Additional barriers included economic stability, family support and the presence of depression (Caon et al. 2010). Adherence to treatment has been associated with improved health outcomes, lower risk of relapse, decreased hospital admissions, and decreased healthcare provider office visits (Steinberg, Faris, Chang, Chan, & Tankersley, 2010). A relationship that is based on open communication between the individual with MS and their

healthcare provider can have a significant influence on their adherence to treatment regimens and overall QoL (Rinion, Buch, & Verdun, 2011).

Healthcare Provider Engagement

Bakken et al. (2000) defined healthcare provider engagement as dimensions of access to healthcare, information sharing, involvement of the client in decision-making and self-care activities, respect and support of the provider for the client's choices, and the management of client concerns. For this research study, healthcare provider engagement was defined as the patient's perception of the interaction with his or her healthcare provider in terms of the exchange of information, mutual decision-making and involvement in self-care management, respect and support of the provider for the patient's choices, and the management of patient concerns.

Recent research has focused on a shift in healthcare from disease-centered care to patient-centered care as a model for change in caring for those with complex diseases such as MS. Poor interactions with the healthcare provider can have a negative influence on those with MS. White, White, and Russell (2007) found that only 44% of individuals with MS had discussed their emotional wellbeing with their healthcare provider at the time of diagnosis. Because of the complexity of MS, the use of medications alone is inadequate. Persons with MS are in need of accurate information to cope with the day-to-day challenges. Lejbkowicz et al. (2012) revealed that poor communication among those with MS and their healthcare provider can lead to suboptimal care. Specific barriers to optimal healthcare included inadequate information sharing, inadequate education about the proper use of medications, and poor treatment instructions. Additional barriers included limited access to staff members to clarify questions, inadequate access to medications, and suboptimal follow-up schedule (Lejbkowicz et al., 2012).

Functional Ability

MS can affect an individual's physical, cognitive, and social functioning (Brodkey et al., 2011). Since disease progression is highly variable, each individual can experience a unique set of symptoms. Some of the most common physical symptoms of MS include pain, fatigue, peripheral neuropathy, bowel and bladder incontinence, visual changes, sexual dysfunction, and inability to walk (D'Arcy, 2012). Psychological manifestations include depression and cognitive impairment (Patti et al., 2011). Additionally,

individuals with MS can experience unemployment, social isolation, family dysfunction, and relationship difficulties (Brodkey et al., 2011).

<div align="center">Significance</div>

Multiple sclerosis affects more that 2.3 million people worldwide (National MS Society, [MS Society] 2013). Geographic location, environment, and genetic components are among the most documented associations with the disease. MS is more prevalent in Europe, the United States, New Zealand, and Australia. It is much less common in Asia and Africa. African men have a 40% lower risk of MS than White men (Ramagopalan & Sadovnick, 2011). Globally, women are 2 to 3 times more likely to have MS (Rumrill, 2009b). Globally, MS is more prevalent in the most northern and southern latitudes. The prevalence rate in England and Wales is 100 per 100,000 and as high as 200 per 100,000 in Scotland (Hassan-Smith & Douglas, 2011). Similar prevalence rates have been documented in Australia. The prevalence rate in Hobart, Australia is 75.6 per 100,000 in contrast to 11 per 100,000 in northern Queensland, Australia (Ramagopalan & Sadovnick, 2011).

Currently, 250,000 to 350,000 individuals are living with MS in the United States (MS Society, 2013). In the United States, the reported prevalence of MS per region varies widely depending on the source. About 10,000 new cases of MS occur each year with a steady increase in prevalence since 1950 (Rumrill, 2009b). In 1978, the prevalence rate for MS was 58 per 100,000, while recent estimates within the United States are 99 to 178 per 100,000 (Awad & Stuve, 2010). Noonan et al. (2010) examined prevalence rates in Texas, Missouri, and Ohio. The highest prevalence rates were noted in the northernmost areas of the United States when compared to the southernmost areas. Prevalence estimate data using definite and probable cases of MS was collected from 1998 to 2000. Prevalence rates in Texas were 47.2 per 100,000 compared to 86.3 per 100,000 in Missouri. Ohio had the highest prevalence rate of MS at 109.5 per 100,000. Higher prevalence rates were noted among Whites at 117.9 per 100,000 compared to African Americans at 90.9 per 100,000 in all three states combined. These findings are consistent with global geographic patterns of MS prevalence (Noonan et al., 2010).

Social Issues

Individuals with MS may have limited access to human and social capital. Human capital is the investment in a population in such a way that allows the advancement of skills in order to further contribute

to society (Aday, 2001). A lack of human capital can have a negative influence on the psychological, physical, and social functioning of individuals with chronic illness. Common areas for the investment of human capital include education, job skills, and adequate housing. Increased investments in human capital are associated with improved health outcomes. In contrast, poor investments in human capital limit available resources for coping with personal and economic adversities (Aday, 2001).

Social capital is the quantity and quality of relationships an individual possesses (Aday, 2001). Social capital is important because it provides available resources for those experiencing negative life events. Individuals with increased social capital are likely to have increased physical, psychological, and social wellbeing (Aday, 2001). Social support is important to improve QoL among persons with MS. McCabe et al. (2009) examined changes in QoL, social support, and coping among 382 individuals with MS. The study revealed that individuals with MS experience a higher QoL when increased social support is present (McCabe et al., 2009). In addition to social issues, persons with MS experience individual difficulties such as physical symptoms, and disabilities.

Individual Issues

The daily symptoms and disabilities experienced by individuals with MS may lead to embarrassing public situations and a perceived decrease in QoL. For example, many individuals with MS depend on assistive devices such as wheelchairs for mobility. Such assistive devices are associated with social stigma and presumed disability (Grytten & Måseide, 2006). Public stigma can lead to social isolation and withdrawal from relationships (Grytten & Måseide, 2006).

The physical and psychological effects of MS can intensify without warning and vary in combination throughout the disease course (Rumrill, 2009b). The physiological manifestations of MS are associated with the affected area of the central nervous system. Physical symptoms associated with MS range from blurred vision to inability to stand or walk. Persons with MS often experience incontinence, muscle spasticity, pain, fatigue, extremity numbness, and sexual dysfunction. Additionally, persons with MS experience cognitive changes that can affect attention, conceptual reasoning, executive function, and memory. Affective disorders are also associated with MS, which include irritability, difficulty concentrating, anxiety, bipolar disorder, and depression (Rumrill, 2009b). Persons with MS are 30% to 60% more likely to experience depression compared to individuals with other chronic neurological diseases

(Chakravorty, Buchanan, Johnson, Tyry, & Vollmer, 2010). Symptoms associated with depression have been reported by 41.8% of persons with MS. Among the 41.8% diagnosed with depression, 25% exhibited signs of a major depressive disorder (Baron, Corden, Jin, & Mohr, 2011)

Brief Description of the Theoretical Framework

An adapted version of The Chronic Care Model (CCM) was used to frame this research study (The Chronic Care Model: Improving Chronic Illness Care, [CCM] 2013). CCM outlines the essential components of a healthcare system promoting high-quality chronic disease care. The theoretical model focuses on evidence-based concepts within the community, the health system, self-management support, delivery system design, decision support, and clinical information systems. Overall, the model serves as the basis for empowerment of the individual through shared decision making in concordance with the healthcare system (CCM, 2013) (Figure 1-1).
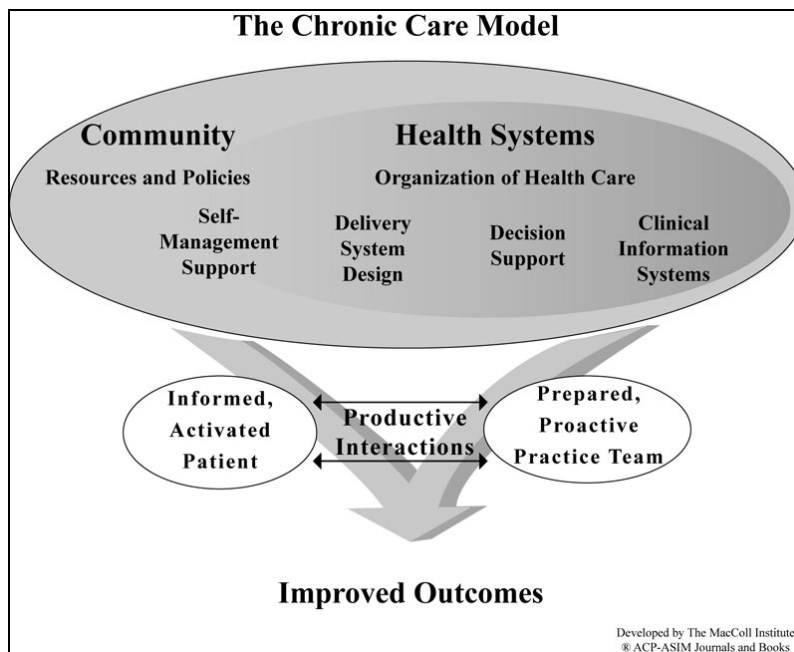

Figure 1-1 The chronic care model

Wagner (1998) originally developed the content for CCM. The content was used as part of a national initiative to improve the care of those with chronic illness across multiple healthcare systems. Because of changes in healthcare, additional components were added to CCM in 2003. These areas within

the healthcare system included patient safety, cultural competence, care coordination, community policies, and case management (CCM, 2013).

Community within CCM serves as a basis to encourage active participation in available resources to meet the needs of the person with chronic illness (CCM, 2013). A healthcare system that partners with community programs and resources can broaden the care spectrum for those with chronic disease. State and local policies, insurance-benefits, and civil laws for persons with disabilities are vital components among those with chronic illness (CCM, 2013).

Healthcare systems in CCM must be dynamic and strive to promote a culture for safe, high-quality care for those with chronic illness (CCM, 2013). Organizations implement improvement strategies that enhance communication and effective care coordination. Data sharing in the healthcare system is supported as an individual with chronic illness transitions across systems and providers (CCM, 2013).

Self-management support in CCM focuses on the empowerment of an individual to become an active manager of their health and healthcare (CCM, 2013). The patient assumes a central role in healthcare and is encouraged to participate in care decisions by setting goals, action planning, and follow-up. This collaborative approach allows the individual with chronic illness to engage in a responsible approach to their health (CCM, 2013).

Delivery system design within CCM is the creation of a healthcare system that takes on a proactive approach to patient care. Individuals with chronic illness have unique needs that are addressed most effectively by a healthcare system that is structured, organized and streamlined. Because individuals with chronic illness constitute a diverse population, health literacy and cultural competence are two important concepts in providing effective long-term care (CCM, 2013).

Decision support is an ongoing collaborative process in CCM (CCM, 2013). Persons with chronic illness must be active participants in their healthcare. Dialogue with the healthcare provider is key. Treatment decisions are based on evidence-based guidelines that are current and relevant. Education methods should be tailored to meet the specific needs of the person with chronic illness. Decision support is part of a continuous feedback loop between the provider, healthcare system, and patient (CCM, 2013).

Clinical information systems within CCM serve as the basis to create a healthcare system that provides ready access for individuals with chronic illness (CCM, 2013). Clinical information systems that

are effective summarize data that can be used to track performance and goal achievement for persons with chronic illness. A comprehensive clinical information system is essential for quality improvement and meeting the needs of the individual with chronic illness (CCM, 2013).

CCM was chosen for use in this study for several reasons. Individuals with MS experience a complex network of disease-related factors requiring a healthcare system that is active, innovative, and comprehensive (CCM, 2013). MS is a disease that affects all aspects of an individual including family and social relationships. CCM was also selected because it is a systems-based model. MS is a long-term disease process and requires ongoing health-related support throughout the life span. Access to healthcare, health information, and cultural competence are important concepts in the management of MS. Finally, CCM was chosen as the basis for this study because it takes a patient-centered and proactive approach to providing care. MS is best managed through active collaboration and a healthcare system that focuses on the anticipated needs of the individual. A model that is based on individualized care and active decision-making is key in managing individuals with chronic illness. The individual assumes a central role in the CCM through participative decision-making and informed collaboration (CCM, 2013). Permission to use this conceptual model was granted by the author (Appendix A).

The CCM has been used extensively in the management of chronic disease. Holm and Severinsson (2012) used the CCM to identify barriers in the management of depression in primary care. Barriers included lack of organizational, administrative, and professional ability to change when promoting the patients self-management (Holm & Severinsson, 2012). Mackey et al. (2012) examined medication adherence among 1823 individuals using the elements of CCM. Increased medication adherence was associated with increased self-management support (Mackey et al., 2012). Dancer and Courtney (2010) reviewed research findings that improve health outcomes for individuals with Type 2 diabetes. Healthcare based on the CCM were found to improve patient outcomes by identifying gaps, defining needs, and the development of innovative care strategies (Dancer & Courtney, 2010). The adapted version of the Chronic Care Model for this study included the integration of healthcare provider engagement, functional ability, treatment adherence, and QoL. Figure 1-2 illustrates the adaptation of the Chronic Care Model for this research study.

Individuals with MS interact simultaneously with both the community and healthcare systems. Social and individual issues interact with self-management support. Social support issues may include the lack of human capital, employment, access to healthcare coverage, and environment. Addressing social issues may lead to productive interactions. Such interactions potentially increase functional ability and treatment adherence. Quality of life may be greatly influenced through this series of interactions.
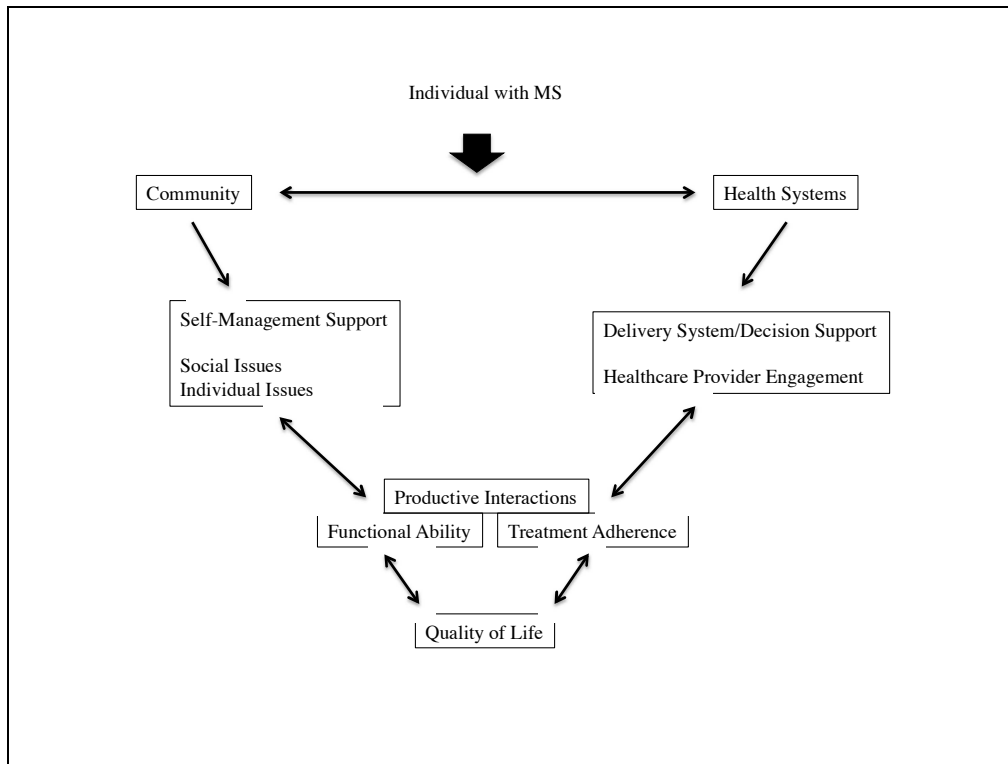
Figure 1-2 Adapted chronic care model

Healthcare provider engagement is associated with delivery system design and decision support. Healthcare providers who are fully engaged with patients can lead to productive interactions. This type of healthcare provider engagement can influence QoL. The following conceptual definitions are synthesized from multiple authors.

Conceptual Definitions

1. Healthcare Provider Engagement – The patient's perception of the interaction with his or her healthcare provider in terms of the exchange of information, mutual decision making and involvement in self-care management, respect and support of the provider for the patient's choices, and the management of patient concerns (Bakken et al., 2000).

2. Treatment Adherence – The extent to which an individual implements the treatment suggested by a healthcare provider with consistency and accuracy (The World Health Organization [WHO], 2013).

3. Functional Ability – The ability to perform activities that encompass physical and cognitive processes.

4. Quality of Life – An overall state wellbeing as perceived by the individual with MS (Forbes, While, Mathes, & Griffiths, 2006).

Chapter Summary

Multiple sclerosis is a multifaceted disease affecting more than 2.4 million people worldwide (MS Society, 2013). Individuals with MS experience varying levels of dysfunction physically, cognitively, and socially. Existing barriers to comprehensive healthcare lead to greater levels of dysfunction and fragmentation in health advancement. Understanding the factors associated with such dysfunction can lead to overall improvements in health and health-related outcomes among persons with MS.

The relationship between healthcare provider engagement, treatment adherence, functional ability, and QoL is a key aspect to improve the overall wellbeing of individuals with MS. Understanding these relationships can serve as the basis for future educational programs for persons with chronic illness. Additionally, further areas of need can be identified for overall healthcare improvement in the management of chronic illness. Individuals with MS face challenges that are unique and complex. Examining the key factors that influence the care of these individuals can lead to greater long-term care management and improved health outcomes.

Chapter 2

Review of Literature

MS is a disease that influences a broad range of social and individual issues. Within the social context, individuals with MS experience impaired social connectedness, limited access to health services, inadequate health information, and poor self-management support. Individual issues associated with MS include physical and cognitive dysfunction. This study focused on the interrelatedness of healthcare provider engagement, treatment adherence, functional ability, and QoL among individuals with MS. These four concepts were examined within the context of social and individual issues associated with MS.

Search Strategies

Databases searched, using EBSCO, included Academic Search Complete, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, MEDLINE, PsycINFO, Psychology, and Behavioral Sciences Collection, ERIC, and PsycARTICLES. Table 2-1 displays the keywords used in the search for relevant literature. Qualitative and quantitative articles were included in this literature review. A timeframe from 1965 to 2013 was used in the search for articles related to the research concepts. The search was narrowed by only using articles from peer-reviewed journals that contained the research study concepts. Articles were then selected based on their relevance to answering the research question. Approximately 40 articles were selected because the researchers measured concepts relevant to the study. Articles were organized into the categories of disease physiology, healthcare provider engagement, treatment adherence, functional ability, and quality of life. All articles were reviewed for potential contribution to the research study.

Table 2-1 Search terms and article results

Search Terms	Article Results
treatment adherence AND multiple sclerosis	138
functional ability AND multiple sclerosis	107
healthcare provider AND multiple sclerosis	28
healthcare provider AND engagement AND multiple sclerosis	2
quality of life AND multiple sclerosis	2,455

Factors Associated with Multiple Sclerosis

Environmental factors such as infectious diseases, smoking, and lack of vitamin D exposure have been associated with the onset of MS (Wingerchuk, 2011). Among persons with MS, 99% test positive for the Epstein-Barr virus (EBV). Individuals that are EBV negative have a 10 times lower risk of developing MS when compared to EBV positive persons (Lauer, 2010). Smoking has been shown to double the risk of developing MS and can accelerate the progression of the disease (Wingerchuk, 2011). Smokers with MS have greater brain atrophy and an increased amount of brain lesions when compared to nonsmokers (Wingerchuk, 2011). Low vitamin D levels are associated with increased risk of MS, decreased levels of functional ability, and increased brain atrophy (Hassan-Smith & Douglas, 2011). Following diagnosis, a high degree of individuals with MS have low vitamin D levels (Wingerchuk, 2011). Moreover, decreased levels of vitamin D among persons with MS are thought to be associated with the latitudinal gradient of MS prevalence. The UV light exposure required for vitamin D production is less with increased distance from the equator, especially in winter (Wingerchuk, 2011).

MS is the most common cause of neurological deficit in young and middle-aged individuals (Johnson, Terrell, Sargent, & Kaufman, 2007). The mean age of disease onset is 30 years with 70% of first symptoms reported between 20 and 40 years of age (Hassan-Smith & Douglas, 2011). Women are twice as likely to develop MS than men (Rumrill, 2009b). Disease onset is rarely reported among individuals younger than 10 and older than 60 years of age (Hassan-Smith & Douglas, 2011).

Self-Management Support

Social and Individual issues have a profound influence on QoL among persons with MS (Hwang et al., 2011). Due to its complexity; MS is one of the most difficult diseases to cope with physically and psychologically. A broad range of intrusive factors creates an unusually difficult life course for individuals with MS. Social isolation, financial hardships, and discrimination are among the most common factors associated with a negative QoL. Individual issues such as physical dysfunction, cognitive impairment, and emotional disorders, also negatively influence QoL (Hwang et al., 2011).

Social and Psychosocial Adjustment

The psychosocial adjustment that is associated with MS creates significant internal and external stressors. Social isolation, depression, and strained relationships are among the most commonly reported

burdens following the diagnosis of MS (Irvine et al. 2009). Irvine et al. (2009) found that a combination of impaired physical ability and the psychosocial impact of MS negatively influenced every aspect of the individual's life. Individuals experienced feelings of loss and significant psychological adjustments following being diagnosed with MS. As the disease progressed, fatigue was cited as one of the most prominent factors related to limiting an individual's ability to function socially and professionally (Irvine et al., 2009). Many participants in the study cited that they avoided crowds due to the embarrassment associated with the physical limitations related to MS. Moreover, a loss of self-identity and independence was reported among participants, placing a strain on psychological wellbeing (Irvine et al., 2009). To overcome these internal and external stressors, individuals with MS make significant life adjustments and adaptations.

Life adjustments and adaptations related to MS involve a complex network based on social support and coping (Irvine et al., 2009). Hwang et al. (2011) examined the three concepts of self-concept, social support, and accessible resources and their correlation with QoL among individuals with MS. The results indicated moderate correlations between adjusted self-concept, a moderate correlation between social support and QoL, and a significant correlation between accessibility and QoL (Hwang et al., 2011). Many individuals reevaluate their self-concept and draw upon the support of family and friends. Significant life transitions are found based on the individual's perception of the disease, self-appraisal, and interpersonal relationships (Irvine et al., 2009). McCabe et al. (2009) found that over a two-year period, individuals with support systems reported increased QoL. These findings indicate that individuals with MS adapt to their illness over time through a network of social support and coping strategies (McCabe et al., 2009).

Financial Issues

Persons with MS incur a significant economic burden. The exceptionally high cost of prescription medications and the assistive devices associated with MS may be inadequately covered by medical insurance (Oleen-Burkey, Castelli-Haley, Lage, & Johnson, 2012). The consequences of inadequate treatment can lead to loss of functional ability and poor work productivity. The financial burden of MS is intensified because the onset of the disease often occurs between 20 and 40 years of age (Rumrill, 2009a). During this time, individuals are typically developing careers, caring for children, and managing financial

commitments such as a home mortgage. The influence of suddenly losing income or being forced into retirement can have devastating financial consequences. Sudden changes in income and inability to cope with the increased financial burdens can dramatically influence QoL.

In a qualitative study of 26 individuals with MS, De Judicibus and McCabe (2007) discovered that 20 participants reported a loss of income associated with the progression of MS. Many participants experienced changes in employment and inability to support their current financial commitments. Quality of life was negatively influenced by these financial hardships creating interpersonal relationship strain, lower standards of living, and increased stress levels (De Judicibus & McCabe, 2007).

The costs associated with MS can be classified as direct or indirect. According to Oleen-Burkey et al. (2012), direct costs are detection, treatment, rehabilitation, and long-term care associated with an illness. Indirect costs are associated with a loss of productivity at home, work, early retirement, and premature mortality. Oleen-Burkey et al. (2012) revealed the annual total direct and indirect cost per individual with MS to be $35,232. Within the total direct and indirect cost, 73% represented direct cost and 27% represented indirect cost. Individuals experiencing one or more relapses during the year experienced higher costs versus those who were clinically stable ($38,458 versus $28,669, $p = 0.0004$). The direct and indirect total cost of one relapse was estimated to be $4,449 (Oleen-Burkey et al., 2012).

The unpredictable progression of MS creates a broad range of disability levels and economic costs. Individuals with MS are twice as likely to be hospitalized overnight or see a healthcare professional compared to those without MS (Naci, Fleurence, Birt, & Duhig, 2010). The cost of maintenance medications, assistive devices, and home modifications are dependent on the level of disability among persons with MS. Table 2-2 gives an overview of common disease modifying medications and their costs (Rosenzweig, et al. 2010).

Table 2-2 Disease modifying therapy drugs and annual cost

Drug Class	Delivery Method	Annual Cost
Immunomodulator	Intramuscular injection	$39,636
Interferon-beta	Subcutaneous injection	$35,418
Monoclonal antibody	Intravenous injection	$37,317
Anthracenedione	Intravenous injection	$2,040-$4,080

Since MS is a lifelong disease, medications are a part of long-term therapy. As a result, individuals with disabilities often depend on their employers for assistance with the cost of medical coverage. Unemployment rates among individuals with disabilities are high. According to Roessler et al. (2011), unemployment rates among persons with MS range from 40% to 80%. De Judicibus & McCabe (2007) found that loss of employment was among the most important factors associated with the financial burden of MS. Functional limitations and workplace discrimination were among the most frequently cited reasons for unemployment among individuals with MS (Wallace, 2008).

Discrimination

Discrimination by employers is reported among individuals with MS. In a study of 200 persons with MS, Roessler et al. (2011) discovered that 29.5% experienced employment discrimination and 48% reported failure of their employer to provide adequate accommodations on the job (Roessler et al., 2011). Rumrill (2009a) reported that 29.9% of individuals with MS cited unlawful termination as a source of workplace discrimination. Additionally, 9.8% of individuals with MS reported terms and conditions of employment as a source of workplace discrimination along with 6.7% reporting harassment (Rumrill, 2009a). As a result, 80% of individuals with MS are unemployed within ten years of diagnosis (Vickers, 2012).

Individual Issues

A number of individual issues are associated with MS. These issues include the physical symptoms associated with MS and their relationship to QoL. Persons with MS experience physical symptoms that make it difficult to function on a daily basis. Consequently, these disruptive symptoms make it challenging or impossible to lead a normal life. Among the most common physical symptoms associated with MS are fatigue, spasticity, poor ambulation, visual impairment, and bowel and bladder dysfunction (Rumrill, 2009b)

Fatigue is the most frequently reported and intrusive physical symptom associated with MS. Schapiro (2009) described three categories of fatigue. Normal fatigue is tiredness associated with experiences throughout the day. Individuals with normal fatigue are taught to restructure their day to minimize periods of fatigue. Short-circuiting fatigue results over exertion. Short-circuiting fatigue is temporary and can resolve with rest. Lassitude fatigue, or MS fatigue, is denoted by a sense of

overwhelming tiredness with a sudden onset and without warning. MS fatigue is treated through a combination of pharmacological therapy and rest (Schapiro, 2009).

Spasticity is defined as uncoordinated movements of contraction and relaxation (Rumrill, 2009b). Individuals with spasticity experience pain and difficulty coordinating movements. The spasticity associated with MS results in significant muscle stiffness. Aggressive stretching and pharmacological therapy is used to relieve spasticity.

Two-thirds of individuals with MS experience difficulties with ambulation (Schapiro, 2009). The use of assistive devices is common and may include canes, crutches, walkers, or motorized scooters. Poor ambulation and MS is associated with balance problems and weakness in the lower extremities. Difficulties with ambulation range from mild alterations to inability to stand or walk (Rumrill, 2009b). Alterations in ambulation can create significant barriers to maintaining a productive lifestyle and ultimately a poor QoL.

Visual impairments are associated with MS. Blurred or double vision is a common, but often temporary, occurrence (Rumrill, 2009b). Optic neuritis is often the first symptom of MS resulting from inflammation of the optic nerve. Additional visual impairments encompass weakening of the eye muscles and nystagmus. Visual impairments make it increasingly difficult for the individual with MS to perform daily activities, such as driving, which places an additional strain on independence (Rumrill, 2009b).

Bowel and bladder dysfunction is a common occurrence associated with MS. Commonly reported urinary problems include urgency, frequency, hesitancy, and incontinence (Schapiro, 2009). Between 43% and 73% of persons with MS experience bowel dysfunction (Gulick, 2011). Constipation and fecal incontinence are among the most common symptoms. These symptoms can negatively affect QoL and place a significant burden on individuals with MS (Gulick, 2011).

Overall, a constellation of social and individual issues negatively influences QoL among persons with MS. The complexity of MS requires the individual to adapt through a unique process encompassing adjusted self-concept, social support, and accessibility of services. These three concepts are important to facilitate disease adaptation and provide an avenue for social, community, and healthcare engagement. Increased engagement can improve overall functioning and QoL. This study will focus on QoL and its relationship to healthcare provider engagement, functional ability, and treatment adherence.

Delivery System and Decision Support

Healthcare Provider Engagement

Individuals with MS require healthcare provider engagement to ensure a high QoL. The relationship between the healthcare provider and the individual with MS must be based on mutual trust, effective communication, and productive interactions. Healthcare provider engagement among individuals with MS is important to improve continuity of care, increased information sharing, identify unmet needs, and coordination of care (Golla, Galushko, Pfaff, & Voltz, 2012). Consistent with Bakken et al. (2000), healthcare provider engagement is the patient's perception of the interaction with his or her healthcare provider in terms of the exchange of information, mutual decision-making and involvement in self-care management, respect and support of the provider for the patient's choices, and the management of patient concerns. The unpredictable and unique progression of MS underscores the importance of healthcare engagement among individuals with MS. Once diagnosed, individuals with MS experience a complex network of physical, psychological, and social issues. Previous literature indicates only 44% of individuals with MS have discussed their emotional wellbeing with their healthcare provider at the time of diagnosis (White et al., 2007). People with MS are not a homogeneous population as MS affects each individual differently. An engaging relationship with healthcare providers is important in order to address the unmet needs of people with MS.

Forbes et al. (2007) examined self-reported needs in the MS population. Among the most important needs related to healthcare included effective disease-modifying therapies, improved specialty care, and effective information sharing. Additional areas of need included effective rehabilitation services and community support (Forbes et al., 2007). These findings reinforce the importance of a holistic healthcare approach to caring for those with MS. Healthcare providers must care for those with MS by improving collaborative efforts to ensure effective treatment.

In a similar study, Golla et al. (2012) used a qualitative approach to examine the unmet needs of people with MS. Physicians, nurses, and social workers were asked to identify the most important unmet needs of those with MS. Diverse services such as home assistance for those with greater disability and managing everyday life were identified by the healthcare providers as key areas of unmet needs among persons with MS (Golla et al., 2012). Similarly, persons with MS expressed their need for sensitive

conversations with their healthcare provider and the desire to be treated with respect. In addition, persons with MS expressed their need for an open relationship with their healthcare provider based on continuity and individualism (Golla et al., 2012). These findings are important because they underscore the importance of healthcare provider engagement to ensure effective treatment and overall QoL.

Treatment adherence and QoL in MS are also influenced by healthcare provider engagement. Individuals with a high degree of healthcare provider engagement were more likely to adhere to treatment regimens and reported better QoL (Buchanan, Kaufman, Zhu, & James, 2008). In addition, individuals who perceived their healthcare provider as empathetic and concerned for their needs were more likely to remain on disease-modifying therapies (Buchanan et al., 2008). Health system-based barriers to optimal adherence include less than adequate information about the disease, limited information about the benefits and risks of treatment, ineffective education about the proper use of medications, and poor treatment instructions (Lejbkowicz et al., 2012).

Healthcare provider engagement is a major factor related to the overall wellbeing of persons with MS. Patient engagement is important to ensure that individuals with MS are well informed and have access to accurate and appropriate health information. Although limited research has been conducted to determine the long-term effects of engagement, individuals with MS can benefit from a relationship built on empathy and accurate information sharing. Improving healthcare engagement in MS is important to ensure the needs of this vulnerable population are met.

<div align="center">Functional Ability and Multiple Sclerosis</div>

An individual's ability to function normally can be greatly compromised by MS. Physical and cognitive dysfunctions are associated with inactivity and poor social engagement (Motl, Snook, & Schapiro, 2008). This inactivity can have a negative influence on activities of daily living such as meaningful work and social interaction (Motl et al., 2008). Overall, these physical and cognitive impairments have a negative influence on QoL by limiting independence and impeding activities of daily living.

Physical Dysfunction

The most common symptoms reported with MS include fatigue, balance problems, bowel and bladder dysfunction, and generalized weakness (Brodkey et al., 2011). Additional reported symptoms

include stiffness, muscle spasms, pain, and difficulty walking (Motl et al., 2008). Fatigue is among the most common symptom and is reported in 75% to 95% of persons with MS (Mollaoglu & Üstün, 2009). The fatigue associated with MS is differentiated from a normal sense of tiredness. Individuals with MS experience an overwhelming sense of exhaustion that affects their ability to function at a normal level (Schapiro, 2009).

The physical and cognitive dysfunction associated with MS can have a negative influence on a person's ability to perform activities of daily living. Månsson and Lexell (2004) examined the performance of activities of daily living (ADL) among individuals with moderate to severe MS. All participants were noted to experience difficulties with motor function while performing ADL's ($n = 44$) and 68% of the participants had alterations in cognitive processing ability. Both men and women participants were noted to have limitations in self-care, transfer, and locomotion. Additionally, the overall quality of performing ADL's was reduced (Månsson & Lexell, 2004). Goverover et al. (2005) examined the functional ability of persons with MS using subjective and objective measures as compared to healthy controls. MS participants reported more difficulties with functional tasks relative to healthy controls. Participants also performed significantly worse than healthy controls on objective performance-based testing (Goverover et al., 2005). In an innovative approach to examining functional ability, Goverover, O'Brien, Moore, and DeLuca (2010) used Actual Reality, a performance-based testing approach measuring every day life activities. Actual Reality uses the Internet as a means to perform common tasks that a person might use on a day-to-day basis. Goverover et al. (2010) discovered that individuals with MS experienced significantly more difficulty performing daily tasks, such as purchasing airline tickets, when compared to healthy controls. Individuals with MS committed more errors when performing common Internet-based tasks and required more prompting as compared to controls (Goverover et al., 2010).

Pike, Jones, Rajagopalan, Piercy, and Anderson (2012) evaluated the burden of walking and mobility problems among individuals with MS in five European countries. In a cross-sectional Study Pike et al. (2012) found a majority of individuals with MS experienced walking and mobility problems. Many participants reported difficulty walking as their most intrusive symptom of MS, and that it interfered with their ability to work (Pike et al., 2012). In a similar study across six European countries, Kobelt, Berg, Lindgren, Fredrikson, and Jönsson (2006) reported that work capacity decreased as physical disability

increased. Salter, Cutter, Tyry, Marrie, and Vollmer (2010) assessed the influence of reduced mobility on ADL and socioeconomic status among persons with MS. Decreased mobility was associated with unemployment and decreased full-time work status (Salter et al., 2010). These findings can have profound negative effects on overall QoL and overall mental health of the individual with MS.

In this research study, the Barthel Index was used to measure functional ability. The Barthel Index is a 10-item scale that measures activities related to daily living (Mahoney & Barthel, 1965). The scale contains items related to feeding, grooming, dressing, bowel and bladder function, toilet use, and mobility. Individuals are asked to rate their ability to perform activities on a 0-10 or 0-15 scale depending on the item. Total scores are summed with higher scores indicating a higher degree of functional ability (Mahoney & Barthel, 1965).

<div align="center">Cognitive and Mood Disorders</div>

In addition to physical dysfunction, MS can negatively affect executive function. Previous literature indicates that 54% to 65% of individuals with MS experience cognitive dysfunction (Peyser, Rao, LaRocca, & Kaplan, 1990). Moreover, mood disorders such as depression are common among persons with MS (Wallin, Wilken, Turner, Williams, & Kane, 2006). These psychological burdens can greatly affect functional ability and overall QoL.

Depression and Anxiety

Depression is the most common mood disorder associated with MS (Solari et al., 2004). An estimated 10% to 41.8% of individuals with MS experience depression (Wood et al., 2013). Anxiety is also common with MS with 23.5% to 41% of persons with MS reporting the disorder (Wood et al., 2013). These mood disorders are often exacerbated by the physical symptoms associated with MS and can have a negative synergistic effect. High levels of physical dysfunction have been associated with increased levels of depression, anxiety, and fatigue (Wood et al., 2013). In a longitudinal cohort study of 198 persons with MS, Wood et al. (2013) found that 18.5% of participants were affected by depression, while 44.5% were affected by anxiety, and 53.7% experienced fatigue. A novel finding of this study was that depression, anxiety, and fatigue occurred concurrently in MS ($p < 0.001$) with no one disorder reported alone (Wood et al., 2013).

The depression and anxiety associated with MS interfere with daily activities and evoke thoughts of self-harm. In a systematic review of literature, Pompili et al. (2012) identified several studies supporting an overall risk of suicide among the MS population. Among persons with MS suicidal ideation was higher for men, younger individuals, and those experiencing social isolation, depression, and alcohol abuse (Pompili et al., 2012).

Current literature indicates a number of reasons for the high rates of depression among individuals with MS. The psychological effects of chronic disease, the effect of direct lesions on the brain that regulate mood, the effects of pharmacological agents that are used to treat MS, and immune dysfunction are common causes of depression among persons with MS (Wallin et al., 2006). Overall, depression and anxiety a have significant negative influence on ADL's and QoL among persons with MS.

Unemployment, changes in social networks, and inadequate coping are associated with depression and MS (Wallin et al., 2006). Williams et al. (2005) found unemployment and depression to be major factors associated with persons with MS. In a study of 451 veterans with MS, Williams et al. (2005) found that unemployed persons with MS were 3.2 times more likely to have depression when compared to those that were employed. MS strains social support systems and limits the ability to independently function. Following diagnosis, many individuals with MS become increasingly reliant on social support as the disease progresses. A lack of social support has been associated with increased levels of depression among persons with MS (Bambara, Turner, Williams, & Haselkorn, 2011). In addition to lack of social support, individuals must implement various coping strategies in order to combat the stress of a chronic debilitating disease. Inadequate coping in chronic disease may result in depression (Bambara et al., 2011).

<div align="center">Treatment Adherence</div>

According to the World Health Organization (WHO), treatment adherence for chronic illness averages 50%. In fact, the WHO suggests that improving treatment adherence may have a greater influence on health than improving any specific medical treatment (WHO, 2013). MS is a dynamic disease that affects each individual uniquely. Treatment for MS focuses on symptom management and disease course modification. Key factors in the optimal treatment of MS include disease modification, social support, and symptom management (Ross, 2008). An individualistic approach to treatment based on productive interactions and collaboration is key to improving QoL and overall treatment adherence.

Symptom Management

MS affects each individual differently. Therefore, a range of treatment options is necessary to relieve symptoms and modify the disease course. The progression of MS can lead to primary, secondary, and tertiary symptoms (Brodkey et al., 2011). Examples of primary symptoms include fatigue, clinical depression, spasticity, and bladder dysfunction. Secondary symptoms include contractures, difficulty swallowing, and changes in breathing patterns. Tertiary symptoms include mood disorders such as anxiety and depression. Pharmacological agents are available to treat the symptoms associated with MS. In addition, non-pharmacological agents can include physical therapy, energy conservation techniques, counseling, and bowel regimen training (Brodkey et al., 2011). Complementary therapies such as Tai Chi, biofeedback, and acupuncture have been used to management the physical and emotional symptoms associated with MS (Brodkey et al., 2011). Although most symptoms can be managed effectively, some symptoms such blurred vision and loss of visual acuity are difficult to manage. Relapses or exacerbations are also common with MS and can cause varying degrees of dysfunction.

MS Exacerbations

People with MS experience periods of relapse or exacerbations that last more than 24 hours and result in pronounced symptoms or disabilities (Rosenzweig et al., 2010). During this time, symptoms worsen or become more pronounced. MS relapses are caused by an inflammatory process that occurs as the disease progresses (Rosenzweig et al., 2010). Corticosteroids are used to treat exacerbations, however, this type of treatment can create additional problems if administered in individuals with coexisting disease such as hypertension, cardiac disease, or diabetes. Administering corticosteroids to this population can worsen these conditions (Brodkey et al., 2011). The use of corticosteroids can increase blood sugar, elevate blood pressure, increase the potential for infection, and increase the risk of osteoporosis (MS Society, 2013). Long-term therapy for individuals with MS includes disease-modifying therapies.

Disease Modifying Therapies

Disease modifying therapies are pharmacological agents that slow the progression of MS and reduce the occurrence of relapse (Brodkey et al., 2011). There are currently eight disease-modifying therapies approved by the Food and Drug Administration for MS exacerbations. These therapies include five immunomodulators, one immunosuppressant, one monoclonal antibody, and fingolimod (Gelinya), the

first oral preparation. The immunomodulators have been shown to reduce inflammatory brain lesions by 80% with a concomitant decrease in brain atrophy. These positive benefits, however, do not come without a cost. Immunomodulators are administered via injection and can cause flu-like symptoms, headache, injection-site reactions, anemia, and depression (Rosenzweig et al., 2010). Immunosuppressant therapies have been shown to reduce relapse rates of MS by 33% but adverse effects include treatment related leukemia, cardiovascular toxicity, and infertility. Fingolimod (Gelinya) is available as an oral medication to treat MS, but the long-term effects of this medication have not been studied (Brodkey et al., 2011).

Barriers to Treatment Adherence

Adherence to treatment among individuals with MS is important to obtain the associated benefits such as fewer relapses, decreased disability, and slowed disease progression (Tan, Cai, Agarwal, Stephenson, & Kamat, 2011). In other chronic conditions, such as hypertension and HIV, poor adherence to medication regimens has been associated with worsening of the disease and increased healthcare costs (Campbell et al., 2005). Additionally, problems with treatment adherence in chronic health conditions can lead to increased patient mortality and poor QoL (Treadaway et al., 2009). Discontinuation of treatment rates among individuals with MS range from 20% to 50% within the first two years of treatment (Klauer & Zettl, 2008b; Portaccio, Zipoli, Siracusa, Sorbi, & Amato, 2008). Factors associated with nonadherence include treatment administration difficulties, medication side effects, social characteristics, and level of education (Ross, 2009).

(Ross, 2008) found medication adverse effects and the perceived lack of efficacy were associated with disease modifying therapies and non-adherence. Previous studies reported that 22% to 51% of individuals cite adverse effects as the reason for discontinuing their medications (Ross, 2008). Many individuals with MS may have unrealistic expectations related to treatment, and as a result, discontinue therapy. In addition, the perceived lack of efficacy can be fueled by medical mistrust and general intolerance of medication usage. In a study examining discontinuation of treatment, 23% to 52% of individuals ($n = 632$) reported lack of medication efficacy as the reason (Río et al., 2005).

Bruce, Hancock, Arnett, and Lynch (2010) examined treatment adherence in MS related to emotional status, personality, and cognition. Emotional wellbeing was strongly associated with treatment adherence. Among 55 individuals with MS, 63% with a mood disorder or anxiety symptoms exhibited poor

adherence. Individuals with MS and a mood disorder were found to be five times more likely to be noncompliant when compared to those without a mood disorder (Bruce et al., 2010). This is important given the high rates of depression and anxiety among individuals with MS. Personality traits were also found to be an important indicator of adherence among persons with MS. Participants who were more organized and conscientious were found to have higher rates of adherence (Bruce et al., 2010). This reinforces the importance of teaching programs focusing on structure and organization to improve overall wellbeing among persons with MS.

Treatment adherence among persons with MS is also associated with their health delivery system and the perception of treatment. De Seze, Borgel, and Brudon (2012) examined the perceptions and treatment of 202 individuals with MS. In this sample, 26.2% of participants reported skipping medication once in the past three months. In addition, 18% of participants had interrupted their treatment for at least a week. Patient age and information about MS were two factors cited for non-adherence. In this sample, 42.6% reported that they had been well informed about their disease. Older patients were found to be more adherent to medication therapy (De Seze et al., 2012).

Overall, individual characteristics, emotional wellbeing, education, and adverse medication effects can serve as barriers to treatment adherence among individuals with MS. The consequences of poor treatment adherence can lead to a decrease in QoL. Although much attention has been given to medication adherence, few studies have focused on general adherence and QoL among persons with MS. General adherence is the extent to which an individual implements the treatment suggested by a healthcare provider with consistency and accuracy (The World Health Organization [WHO], 2013).

<center>Quality of Life</center>

Quality of life (QoL) can be viewed as the overall wellbeing of an individual. Health- related QoL refers to the perceived influence of disease on an individual's wellbeing (Gurwell & Berger, 2012a). Assessing QoL among persons with MS is difficult due to the complexity of the disease. Individuals with MS experience a range of factors negatively affecting physical, psychological, and social wellbeing. In a review by Benito-León, Manuel Moralest, Rivera-Navarro, and Mitchell (2003), several factors were identified that contributed to poor QoL among persons with MS. Physical symptoms, changes in life course following diagnosis at an early age, loss of control due to the unpredictability of the disease, lack of a cure,

and risks associated with treatments were associated with decreased QoL (Benito-León et al., 2003). A reduced QoL can interfere with a person's ability to maintain employment, carry out leisure activities, and maintain healthy relationships.

In a study of 323 individuals with MS, Flensner, Landtblom, Söderhamn, and Ek (2013) found that work capacity and health-related QoL were influenced by the physical symptoms. Fatigue was found to be the most significant contributing factor related to work capacity and QoL. Study participants with the capacity to work reported less fatigue than those with no capacity to work (Flensner et al., 2013). In a systematic review of literature from 1996 to 2006, Krokavcova et al. (2009) found that individuals with self-rated good health are more likely to be employed. Additionally, decreased QoL is associated with the burden of increased direct and indirect medical costs (Gurwell & Berger, 2012a). The findings of these studies indicate that QoL among individuals with MS is significantly associated with the physical symptoms of the disease.

In addition to physical symptoms, cognitive dysfunction, depression, and disability are among the most documented factors affecting QoL (Gurwell & Berger, 2012a). Forbes et al. (2006) examined common problems associated with MS and health-related QoL. Among a sample of 929 participants, fatigue, pain, employment, and depression were associated with decreased health-related QoL. Among those who participated, fatigue was the most cited symptom at 93%, followed by depression at 75%, and pain at 73%. Participants reported employment and relationship problems at 60% and 52% respectively (Forbes et al., 2006). The findings of this study highlight the overall negative synergistic effect that physical and emotional dysfunction can have on persons with MS by limiting the ability to function socially and professionally.

Cognitive dysfunction is commonly associated with decreased QoL among people with MS. Gold et al. (2001) compared 80 MS individuals with cognitive dysfunction and 107 individuals without cognitive dysfunction. Individuals with cognitive impairment were found to have increased levels of depression and anxiety along with decreased QoL (Gold et al., 2001). Benito-León et al. (2003) examined QoL among 191 individuals with MS and cognitive impairment while controlling for depression. Poor cognition was associated with decreased QoL (Benito-León et al., 2003).

Overall, QoL among individuals with MS encompasses a wide range of physical, psychological, and social processes. To gain a greater understanding of this process, it is important to examine specific relationships that can influence overall wellbeing. Healthcare provider engagement, treatment adherence, and functional ability are factors that may contribute to QoL among persons with MS.

<div align="center">The Research Gap</div>

MS is a disease that affects every aspect of an individual's life. The physical, psychological, and social dysfunction accompanying the disease can have devastating effects that can decrease QoL. The purpose of this study was to examine the relationships between healthcare provider engagement, treatment adherence, functional ability, and QoL. Although these concepts have been studied over time, albeit inconsistently, no studies have examined the importance of these concepts concurrently. The current study examined these concepts in order to gain a greater understanding of their interrelationships and their influence on the health and wellbeing of individuals with MS.

Chapter 3

Methodology

The purpose of this study was to examine the relationships among perceived healthcare provider engagement, treatment adherence, functional ability, and QoL among persons with MS. This chapter will include a description of the methods of the proposed study. It will include discussions of the research design, sample, setting, measurement, data collection, and data analysis.

Research Design

The study had a descriptive correlational design. Descriptive correlational studies are used to examine relationships within a given situation (Grove, Burns, & Gray, 2013). Examining the relationships among variables may provide the basis for further interventional designs (Grove, Burns, & Gray, 2013). This type of design was chosen to gain a greater understanding of the interrelatedness of healthcare provider engagement, treatment adherence, functional ability, and QoL.

Sample and Sampling Method

Statistical power was calculated using G*Power (Faul, Erdfelder, Lang, & Buchner, 2007). A priori power analysis employing Pearson's Product-Moment correlational analysis indicated that a minimum of 85 participants was required with a statistical power of .80, an alpha level of .05, and an anticipated r of 0.30. To allow for participants who did not answer all items on the instruments and to enhance the geographical diversity of the sample, the desired sample size was set for 150 initially and later increased to 200 due to the response being higher than expected. The sample for this study included individuals 18 years or older with a diagnosis of MS. Nonprobability convenience sample was used for this study. Convenience sampling allowed the researcher to recruit the most participants. Additionally, a snowball sampling method was used to recruit subjects.

Setting

The setting for this study was the location in which the participants had access to the Internet. Participants were asked to complete an online survey at their convenience. The online survey was distributed to participants by email through electronic mailing lists. Site distributions included national MS

organizations, healthcare provider offices, and MS support groups. Alternative data collection sites included social media such as Facebook™ or Twitter™.

<div align="center">Measurement Methods</div>

Four measures were used to evaluate the four concepts of healthcare provider engagement, treatment adherence, functional ability, and QoL. The measures included the Engagement with Healthcare Provider Instrument, the Medical Outcomes Study General Adherence Scale, the Barthel Index, and the Leeds Multiple Sclerosis Quality of Life Questionnaire. The study concepts, its related measure, and the number of items within the measure are presented in Table 3-1. Because of the physical limitations of persons living with MS, reliable and valid measures with the fewest items were selected to minimize subject burden.

<div align="center">Table 3-1 Concepts and related measure</div>

Concept	Measure	Number of Items
Healthcare Provider Engagement	Healthcare Provider Engagement Instrument (Bakken et al., 2000)	13
Functional Ability	The Barthel Index (Mahoney & Barthel, 1965)	10
Quality of Life	Leeds Multiple Sclerosis Quality of Life Questionnaire (Ford et al., 2001)	8
Treatment Adherence	Medical Outcomes Study General Adherence Scale (Hays et al., 1994)	5

Engagement with Healthcare Provider Instrument

Instruments have been developed to measure patient engagement. One such instrument, the Patient Activation Measure (PAM), is a self-reported measure to assess a patient's knowledge, skill, and confidence for self-management of one's health or chronic condition (Hibbard, Mahoney, Stockard, & Tusler, 2005) Four levels of activation are noted within the PAM model. At the lowest level, patients are overwhelmed and may not be ready to take control. At level two, the patient realizes they have an active role in the healthcare system. At the third level, patients are beginning to take action, but still lack confidence to manage their health. At the fourth level, patients struggle to maintain the behaviors they have adopted (Stepleman et al. 2010). Originally developed as a 22-item measure, a short version of 13 items

was developed exhibiting the same psychometric properties as the longer version. Rasch analysis was used to validate the 13-item scale with INFIT and OUTFIT statistics falling within the acceptable range of 0.50-1.50 (Hibbard et al. 2005). To examine the psychometric properties of PAM, Stepleman et al. (2010) administered the instrument to 199 individuals with MS. Cronbach's alpha was reported at 0.88 for the sample (Stepleman et al. 2010). The decision was made not to use this instrument because the data produced are ordinal, which limits the variability. The potential for smaller incremental levels of engagement was viewed as desirable to analyze relationships between engagement and other variables.

To measure healthcare provider engagement, the Engagement with Healthcare Provider Instrument was used because it produces interval level data (Appendix B). Bakken et al. (2000) developed the instrument because no single scale measured all the dimensions of engagement. The measure was developed to examine the relationships between the perceived level of engagement with the healthcare provider and demographic characteristics, health status, and adherence to therapeutic regimen in individuals with HIV (Bakken et al., 2000). The first question of the Engagement with Healthcare Provider Instrument asks the person to select the healthcare provider who was seen on a regular basis and then to keep that person in mind while completing the remaining items. The healthcare provider choices include Doctor, Nurse, Nurse Practitioner, Physician Assistant, and other with a line for the participant to place a response. The remaining 13 items and asks the individual to rate the nature of their interactions with their healthcare provider on a four point scale where 1 = *always*, 2 = *usually*, 3 = *sometimes*, 4 = *never*, and n/a = *no experience*. A total score is calculated with a possible range of 13-52. Mean scores range from 1 to 4. Lower scores indicate that the individual is more engaged (Bakken et al., 2000). All items in this instrument were reverse scored for statistical analysis for a consistent directionality across all instruments.

Bakken et al. (2000) subjected the measure to psychometric testing to assess validity and reliability. Data collected using the tool were analyzed using principal components factor analysis with Varimax rotation. Following testing, a one-factor solution emerged with an Eigenvalue of 8.6 and 66.5% of the variance explained. Internal consistency was evaluated using Cronbach's alpha reliability estimates. Cronbach's alpha is the most widely used statistic to assess internal consistency, one indication of the reliability of a measure (DeVon et al., 2007). Internal consistency refers to how items fit together conceptually (DeVon et al., 2007). According to Nunnally and Bernstein (1994), a reliability coefficient of

0.70 is acceptable for new scales. Bakken et al. (2000) reported a Cronbach's alpha of 0.96 for the

Engagement with Healthcare Provider Instrument with a sample of 707 individuals. Because the

Engagement with Healthcare Provider Instrument has had limited use in previous research studies and has

not been used with patients with MS, an informal feasibility test was conducted of the measure. An online

version of the Engagement with Healthcare Provider Instrument was emailed to 11 individuals with MS to

complete. Levels of engagement ranged from 1.09 to 1.81. Internal consistency testing using Cronbach's

alpha was noted to be 0.73, possibly due to the small sample. None of the volunteers reported any difficulty

in answering the questions either for content or method of data collection. Permission to use this measure

was granted by the author (Appendix C).

Medical Outcomes Study General Adherence Scale

The Medical Outcomes Study General Adherence (MOSGS) Scale was used to measure general

adherence in this study (Appendix D). The measure was developed by the Rand Corporation as part of a

two-year study to examine adherence to treatment regimens in chronic disease and has undergone

significant psychometric testing with diverse samples (RAND Corporation, 2013). The MOSGS was

developed for addressing the adherence of individuals with heart disease, diabetes, and hypertension. The

measure summarizes an individual's tendency to adhere to medical recommendations using five items.

Participants are asked to rate how often statements are true during the past four weeks. Responses include 1

= *none of the time*, 2 = *a little of the time*, 3 = *some of the time*, 4 = *a good bit of the time*, 5 = *most of the*

time, and 6 = *all of the time*. After reverse scoring items 1 and 3, responses are averaged together for a final

score (Hays et al., 1994). Higher scores indicate higher levels of adherence.

Hays et al (1994) used the MOSGS to examine adherence to medical recommendations and health

outcomes with 2,125 participants over a four-year period. Internal consistency of MOSGS was reported to

be 0.78 respectively. In a similar study, Sherbourne, Hays, Ordway, DiMatteo, and Kravitz (1992) used the

general adherence scale to examine antecedents of adherence in 1,198 participants. The internal consistency

of MOSGS was reported to be 0.80. In a two-year study, DiMatteo et al. (1993) used the MOSGS to

examine the relationship between physician characteristics and patient adherence. Internal consistency of

the MOSGS was reported to be 0.78 at baseline and 0.79 at three-year follow-up. Additionally, factor

analysis and multitrait scaling analysis supported the unidimensionality of the five items in the scale. Permission to use this measure was granted by the author (Appendix E).

Measures of Functional Ability

Three instruments were evaluated to measure functional ability in this study. These measures included the Expanded Disability Status Score, the Patient Reported Indices for Multiple Sclerosis, and The Barthel Index.

Expanded Disability Status Score

The Expanded Disability Status Scale (EDSS) is one of the most widely used and reliable instruments for determining functional ability in persons with MS (MS Society, 2013). The instrument must be administered by a trained healthcare professional, but can effectively measure a person's functional ability. Most individuals with MS receive an evaluation that includes an EDSS score at diagnosis and annually. The EDSS is used to evaluate functional ability in five overall categories: pyramidal symptoms, cerebellar function, brainstem function, sensory function, and bowel and bladder function. A ten-point scale is used to determine functional ability using the EDSS. A score of zero is considered normal functional ability while ten is death (MS Society, 2013). The EDSS was not chosen to be used in this research study because it is not a self-reported instrument, requires specific training to administer, and was not feasible for online survey methods.

Patient Reported Indices for Multiple Sclerosis

The Patient-Reported Outcome Indices for Multiple Sclerosis (PRIMUS) was evaluated for use in this study. Doward et al., (2009) developed the measure to examine the impact of MS on an individual from a holistic perspective using rigorous methods of instrument development. The PRIMUS consists of three scales that measure symptoms, activity limitations, and QoL. The number of items on each scale included 22 for symptoms, 15 for activity limitations, and 22 for QoL. These scales can be used as independent measures or in combination (Doward et al., 2009). For this study, only the activity limitations and QoL scales would have been used. Although a well-developed, psychometrically strong instrument, the PRIMUS will not be used due to the developers' contractual restrictions on publishing the psychometric performance of the instrument in this study.

The Barthel Index

To evaluate functional ability, the Barthel Index (BI) was used in this research study. The BI is a 10-item measure related to activities of daily living (Appendix F) (Mahoney & Barthel, 1965). The items include feeding, grooming, bathing, dressing, bowel and bladder care, toilet use, ambulation, transfers, and stair climbing. The measure can be completed by a healthcare professional, or as a self-reported measure. Individual items are scored as 0-10 or 0-15 depending on the item. Individual items reflect an activity such as grooming or feeding. The individual is asked to mark the most appropriate choice such as: 0 = needs help with personal care and 5 = independent face/hair/teeth/shaving. An additional example would be the activity of walking with response choices of 0 = unable, 5 = needs help (verbal, physical, and carrying aid), and 10 = independent. Total scores of the BI range from 0-100 with higher scores indicating a higher degree of independence (Hsueh, Lun, Jeng, & Hsieh, 2002).

The BI has been used widely as a measure of functional ability in diverse populations. Hsueh et al. (2002) examined the psychometric properties of the BI in a study of 118 stroke patients. The authors reported Cronbach's alphas of 0.84 and 0.85 at two different points in time, indicated acceptable internal consistency (Nunnally & Bernstein, 1994). Spearman correlation coefficients for test-retest were reported at 0.92 and 0.94 respectively (Hsueh et al., 2002). Hobart et al. (2001) examined the psychometric properties of the BI in a comparison with the functional independence measure (FIM) among 149 individuals in neurological rehabilitation. The Cronbach's alpha correlation coefficient was reported to be 0.94. Validity testing indicated a correlation of 0.49 between the BI and FIM, with the conclusion that the BI was a suitable measure (Hobart et al., 2001).

The BI is a reliable and widely used measure for functional ability among individuals with MS. Appendix G shows permission to use this scale as granted by the author. In addition to the Barthel Index, the Expanded Disability Status Scale and the Patient Reported Indices for Multiple Sclerosis were evaluated but determined not to be the best instruments to measure functional ability in this study.

Leeds Multiple Sclerosis Quality of Life Scale

The Leeds Multiple Sclerosis Quality of Life (LMSQoL) measure was used to evaluate quality of life in this research study (Ford et al., 2001) (Appendix H). Ford et al. (2001) developed the measure to link

the concepts for health status and QoL among individuals with disabilities. Moreover, the LMS-QoL was developed as a self-reported measure specifically for individuals with MS (Ford et al., 2001).

Three phases were used to develop LMSQoL scale, which included the initial design, preliminary testing, and final testing (Ford et al., 2001). Initial testing of the measure involved 2 focus group sessions of individuals with MS ($n = 30$) to identify individuals main concerns related to MS. Once these main concerns were identified, further discussion was used to identify potential items for the measure (Ford et al., 2001).

Preliminary testing of the LMSQoL scale involved Rasch analysis and internal consistency measures ($n = 25$), test-retest reliability at a two-week interval between administrations ($n = 44$), and the assessment of construct validity through Rasch analysis ($n = 50$) (Ford et al., 2001). Cronbach's alpha coefficient for the initial 25-item scale was reported to be 0.77. Rasch analysis was used to determine items that reflect an underlying construct. Eight items did not reflect the overall construct and therefore, were removed from the model. The new 17 item scale was then subjected to a group of individuals was MS which yielded 3 new items that were added to the scale. The new 20 item measure was then subjected to test-retest reliability measures (Ford et al., 2001).

The 20-item scale was administered to 44 individuals through a postal survey at two-week intervals (Ford et al., 2001). An 82% response rates was reported on the first administration, and a 97% response rate was reported on the second administration. A test-retest reliability was reported at 0.70. Construct validity of the 20-item measure was conducted using Rasch analysis revealing 4 items to be problematic. Following the removal of these four items, a Spearman's rho of 0.77 was reported in a comparison with the General Wellbeing Index (GWBI)(Ford et al., 2001).

In the final testing phase, the 16-item scale was tested using a community-based random, stratified sample of individuals with MS ($n = 180$) (Ford et al., 2001). Scores on the 16-item scale ranged from 16 to 64 with higher scores indicating poor QoL. Cronbach's alpha for the scale was reported at 0.86. Spearman's rank correlation with the GWBI was reported at 0.69 (Ford et al., 2001). Further analysis revealed that 8 items reflected social function and were removed from the scale. The final eight-item scale was found to fit the Rasch model to confirm unidimensionality. Internal consistency was reported to be 0.79 (Ford et al., 2001).

The final eight-item scale consists of questions such as "*I have felt good about my appearance*" or "*My health has affected my relationships with my family*" (Ford et al., 2001). Scoring for each item in the measure ranged from 0-3 with a possible range of 0-24. Individuals are asked to mark a response to the questions 0-3 based on the past month with 0 being "*not at all*" and 3 being "*most of the time*". Items are totaled for a final score. Higher scores reflect poor QoL.

The LMSQoL has been used as a measure of QoL. Nicholl, Hobart, Cramp, and Lowe-Strong (2005) further tested the LMSQoL by collecting data from 90 individuals with MS living in a community setting. The author reported a Cronbach's alpha of 0.71 and a homogeneity coefficient of 0.24 (Nicholl et al., 2005). Hwang, Cvitanovich, Doroski, and Vajarakitipongse (2011) used the LMSQoL to examine the correlation between QoL and adaptation factors ($n = 68$). The authors reported the LMSQoL performed well with a Cronbach's alpha of 0.80 (Hwang et al., 2011). Motl, McAuley, Snook, and Gliottoni (2008) used the LMSQoL measure to examine the relationship between physical activity, QoL, and health-related quality of life among persons with MS. The authors reported a Cronbach's alpha of 0.82 for the LMSQoL scale (Motl et al., 2008).

Overall, the LMSQoL scale is a reliable instrument that measures QoL among persons with MS. Permission to use this scale was granted by the author (Appendix I).

Demographic data was collected in this research study. Specific data included gender, age, marital status, and education level. Additional questions included ethnicity, race, and annual family income. Disease specific demographics included type of MS and number of relapses annually.

Data Collection Procedure

Data collection for this study was conducted by Internet-based survey (Appendix J). All measures were placed in an electronic format as one document. Participants were recruited through national websites such as the National Multiple Sclerosis Society, individual chapters such as the Atlanta MS Society, healthcare provider offices, and MS support groups.

The survey was constructed in Qualtrics and a link to the survey was disseminated via email. Email surveys have several advantages over traditional methods of data collection. Emailed surveys allow participants an easy way to provide data and increase the efficiency of data collection (Hulley, Cummings, Browner, Grady, & Newman, 2007). Additionally, surveys administered through email can be directly

entered into a statistical analysis program (Hulley et al., 2007). There are disadvantages to administering surveys by email. For example, individuals without computer access may not have been able to participate. Additionally, those individuals with severe disabilities may not have possessed the motor skills to negotiate a computer-based survey.

Qualtrics is an online computer program that allows the custom construction and dissemination of surveys to collect data (Qualtrics, 2013). A link was provided via email that allowed participants to anonymously complete the survey. The survey had no identifying data as strict confidentiality procedures were followed.

Ethical Considerations

This study was submitted and approved by an Institution Review Board prior to initiation. Participation in this study was strictly voluntary. Participants had the choice to not participate in this research study without penalty. The initial email contained a cover letter outlining the risks and benefits of participating in this research study. Minimal risks were associated with this study. Participants might have found some questions sensitive relating to level of functioning. There were no direct benefits to participants associated with this study. The first page of the survey contained a waiver of the signature for informed consent. Those who chose to participate, however, contributed to the overall knowledge related to all persons with MS. Participants had the opportunity to decline participation by clicking "no" on the initial page of the survey. Clicking "no" terminated the survey. By clicking "yes" the survey began. No signature was obtained in this research study. IP addresses were not recorded during data collection.

Confidentiality is important in conducting a valid and ethical research study. The researcher ensured confidentiality and anonymity throughout the study. No patient identifiers were used in the data collection process. All electronic data were stored on a password-protected computer with only the researcher having access to the password.

Statistical Data Analysis

The Statistical Package for the Social Sciences (Statistical Packages for the Social Sciences [SPSS], 2012) was used for data analysis in this study. All data were downloaded into the program following collection to create an exploratory model for analysis. Reverse scoring was used with items 1 and

3 of the MOSGS, all items of the Engagement with Healthcare Provider Instrument, and all items of the Leeds QoL questionnaire. This was done to ensure that directional continuity was achieved.

Pearson's Product-Moment Correlation Coefficients were calculated to evaluate the relationships among all study variables. Pearson's Product-Moment Correlation Coefficients are used to determine if a relationship exists among variables (Hinkle, Wiersma, & Stephen, 2003). Values of the correlation coefficients can range from -1.0 to +1.0. A value of +1.0 is considered a perfect positive correlation, while a value of -1.0 is considered a perfect negative correlation. If no relationship among variables exists, a value of zero will be noted (Hinkle et al., 2003). Values of +0.50 or -0.50 are considered moderate positive or negative correlations (Grove, Burns, & Gray, 2013).

According to Grove, Burns, and Gray (2013), four assumptions must be met to use Pearson's Product-Moment Correlation Coefficient.

1. Interval or ratio measurement of both variables
2. Normal distribution of at least one variable
3. Independence of observational pairs
4. Homoscedasticity

All data were examined to ensure that the four assumptions for correlation were met. A test for normality and homoscedasticity was performed prior to the final data analysis. Homoscedasticity refers to data that are evenly dispersed above and below a regression line on a scatterplot. This represents a linear relationship between variables (Grove, Burns, & Gray, 2013).

To examine the differences in perceived healthcare provider engagement, treatment adherence, functional ability, and QoL across the fours stages of MS, data were evaluated to meet the assumptions for Multiple Analysis of Variance (MANOVA). According to Hinkle et al., (2003), three assumptions must be met when performing MANOVA.

1. The samples are independent
2. The scores on the dependent variable are normally distributed
3. Homogeneity of variance

Demographic data were reported as frequencies, percentages, and means. Gender, age, martial status, ethnicity, race, disease stage, and disease type were reported as percentages and frequencies.

Household income was reported as a mean for the sample. Type of disease and number of annual relapses were reported as frequencies.

Following collection, the data was subjected to testing to ensure that all assumptions for Pearson Product-Moment Correlation Coefficient were met prior to analysis. The data met all the assumptions for parametric statistical analysis using Pearson Product Moment Correlation Coefficient.

This chapter described the methodology that was used to conduct this descriptive correlational research study. The research design was used to examine the relationship between healthcare provider engagement, treatment adherence, functional ability, and QoL among individuals with MS. An online survey was constructed via Qualtrics and distributed by email to potential participants. National organizations, healthcare provider offices, and MS support groups served as areas for participant recruitment. Following data collection, the Statistical Packages for the Social Sciences was used for analysis to answer the research questions.

Chapter 4

Findings

This chapter focuses on the findings of a study conducted on factors relating to quality of life in persons with multiple sclerosis (MS). The relationships among disease characteristics, healthcare provider engagement, treatment adherence, functional ability, and QoL were examined. The chapter begins with a discussion of the sample characteristics. The quantitative results related to the research question are presented and chapter ends with a summary of the study findings.

Sample Characteristics

Data were collected using an online survey created in Qualtrics. A link to the survey was disseminated through the National MS Society website and MS support groups throughout the United States. Support groups were contacted in 13 states. States that were contacted to distribute the online survey among support group members are presented in Figure 4-1. Since the specific location of the participants was not included in the survey, some participants may have been from other states, having found the survey through the National MS Society website.
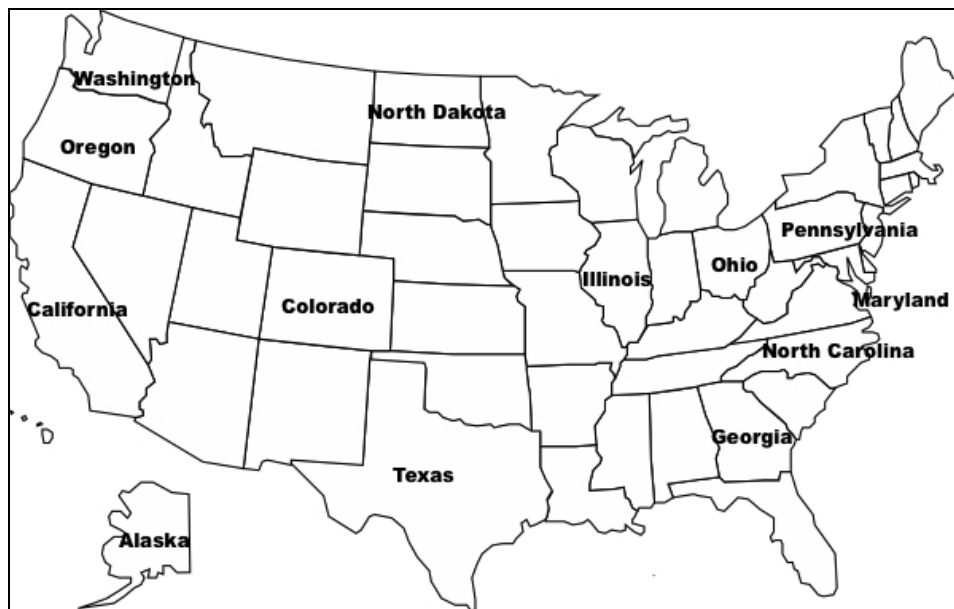
Figure 4-1 States contacted to distribute the MS quality of life survey

Descriptive statistics were computed for the demographic variables using the Statistical Packages for Social Sciences (SPSS version 21). The sample of individuals with MS who participated included 161 with 158 surveys completed. The sample was primarily comprised of female ($n = 132$). Consistent with the inclusion criteria for this study, all participants reported being 18 years old or older. Participants ranged from 26 to 75 years of age ($M_{age} = 51$, $SD = 11.7$). The sample was primarily comprised of White/Caucasian individuals ($n = 132$; 83.5%). The next largest group was African American. Most subjects (150) had at least some college education with almost half (48.1%) having completed an undergraduate degree and over a quarter (27.9%) having earned a graduate degree. Forty-five (28.5%) of participants reported an annual household income greater than $100,000 and 17 (10.8%) reporting less than $30,000 per year. Most were married or had a partner (70.3%). Sample characteristics are presented in Table 4-1.

Table 4-1 Demographics of sample of persons with MS

Subject Characteristics (*N* = 158)	Frequency (%)
Gender	
Female	132 (83.5)
Hispanic Ethnicity	
Yes	7 (4.4)
Race	
White/Caucasian	132 (83.5)
African American	23 (14.6)
Asian	0
Native American	0
Pacific Islander	0
Multiple races	3 (1.9)
Marital Status	
Married	105 (66.5)
Divorced	17 (10.8)
Partnered	6 (3.8)
Single	24 (15.2)
Widow/Widower	6 (3.8)
Total annual household income	
Not reported	3 (1.9)
Less than 30,000	17 (10.8)
30,000-39,000	15 (9.5)
40,000-49,000	19 (12)
50,000-59,000	12 (7.6)
60,000-69,000	11 (7)
70,000-79,000	10 (6.3)
80,000-89,000	13 (8.2)
90,000-99,999	13 (8.2)
100,000 or more	45 (28.5)

Table 4.1 –Continued

Highest level of education completed	
Less than high school	0
High school/GED	8 (5.1)
Some college	30 (19)
2-year college degree	17 (10.8)
4-year college degree	59 (37.3)
Masters degree	36 (22.8)
Doctoral degree	8 (5.1)

Disease and Treatment Characteristics

Because MS is a disease characterized by different stages, participants were asked to self-identify

which stage they were currently experiencing and to quantify the number of relapses they had encountered

in the past year requiring them to seek medical attention. Most ($n = 123$; 77.8%) self-identified as being in

the relapsing-remitting stage of MS while 1.3% ($n = 8$) identified themselves as primary-progressive.

Participants and their disease stages are presented in Figure 4-2.
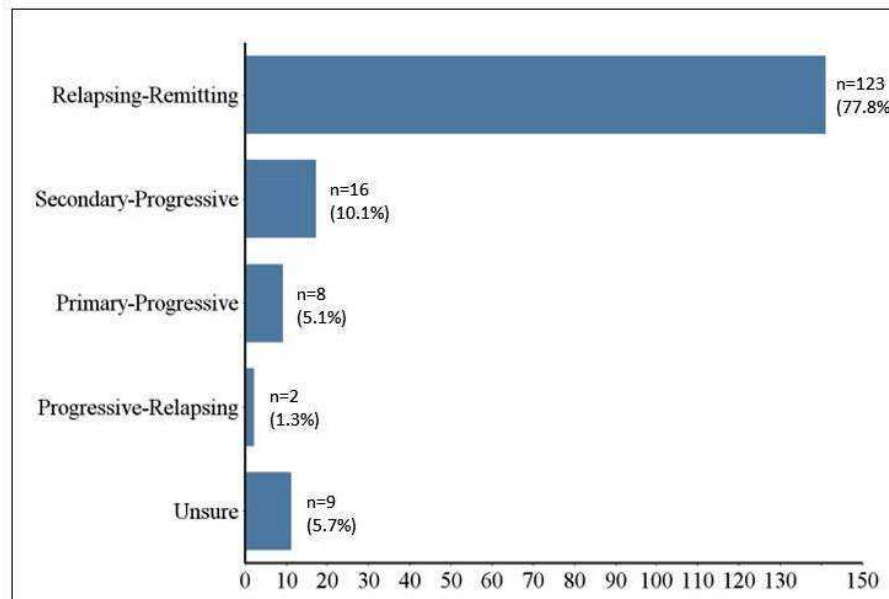
Figure 4-2 Self-identified MS disease stages

Disease relapses were experienced by 59 (37.5%) subjects, with 6 subjects (3.8%) reporting

greater than 4 relapses in the previous year requiring medical attention. In contrast, the majority ($n = 98$)

62.4% had reported zero relapses in the previous year requiring them to seek medical attention. The self-

reported number of MS relapses that required the participants to seek medical attention is presented in

Figure 4-3.
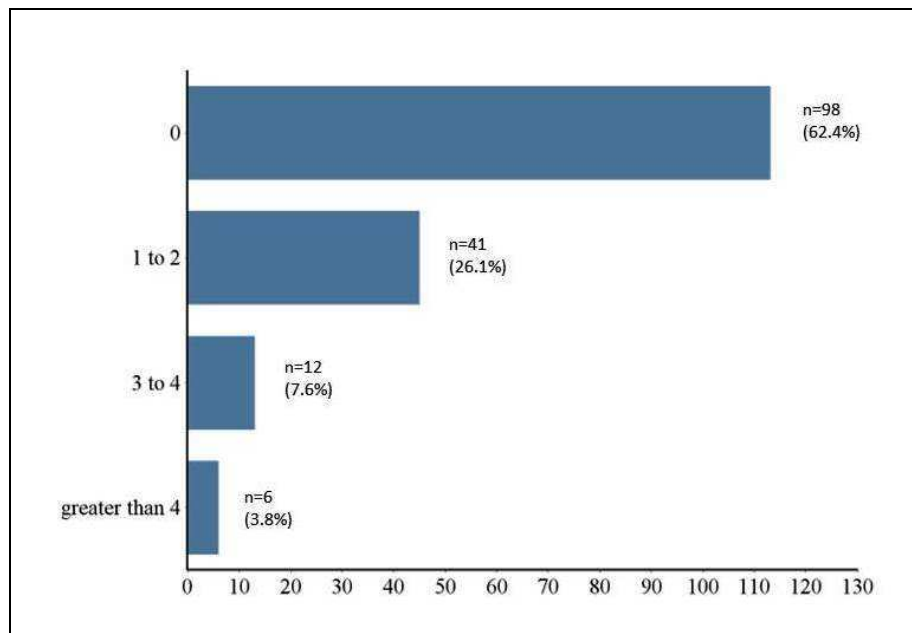
Figure 4-3 Self-identified number of relapses requiring medical attention in one year

The primary healthcare providers of most participants (69.6%) were doctors. Nurse practitioners

and physician assistants were used for primary healthcare by 6.9% of the sample. Almost a quarter reported

seeing multiple providers or selected Other. Participants reported first noticing symptoms from 10 to 69

years of age (M_{age} = 35.2, SD = 11.6), with 158 (98.8%) remembering being told by a healthcare provider

that they had multiple sclerosis. The frequencies for healthcare providers are presented in Table 4-2.

Table 4-2 Primary healthcare providers of persons with MS

Healthcare Provider (N = 158)	Frequency (%)
Doctor	110 (69.6)
Multiple Providers	31 (18.8)
Nurse Practitioner	7 (4.2)
Other	6 (3.6)
Physician's Assistant	4 (2.4)

Measurement Reliability

Four scales were used in this research study: the Engagement with Healthcare Provider

Instrument, the Medical Outcomes Study General Adherence Scale (MOSGS), the Leeds Quality of Life

Questionnaire, and the Barthel Index. Cronbach's alpha coefficients were computed on each instrument to estimate internal consistency. The internal consistency of an instrument is important to ensure that all items are working together conceptually to represent the same construct (DeVon et al., 2007). The Engagement with Healthcare Provider Instrument performed with excellent internal consistency ($\alpha = 0.95$). Cronbach's alpha coefficient estimates for the Leeds Quality of Life measure was 0.85 and 0.84 for the Barthel Index. Additionally, the MOSGS performed well with a reliability estimate of 0.85. Cronbach's alpha reliability estimates for all measures are presented in Table 4-3.

Table 4-3 Internal consistency reliability estimates of instruments used

Measure ($N = 158$)	Mean (SD)	Number of Scale Items	Cronbach's Alpha (α)
Engagement with Healthcare Provider Instrument	3.55 (0.5)	13	0.95
Medical Outcomes General Adherence Scale	4.52 (0.91)	5	0.85
Leeds Quality of Life Instrument	1.63 (0.65)	8	0.85
The Barthel Index	8.90 (1.61)	10	0.84

Description of Study Variables

The scores presented in Table 4-4 indicate that most participants felt that they are engaged with their healthcare provider. One hundred five participants (66.5%) indicated that their healthcare provider always engaged them in their care. Additionally, 113 (71.5%) felt that their healthcare provider always involved them in their decision-making. One hundred eighteen (75.2%) felt a sense of respect from their healthcare provider. According to the data presented, most participants felt engaged with their healthcare provider.

Frequencies from the Medical Outcomes Study General Adherence Scale are presented in Table 4-5 According to the data presented; respondents indicated that they were able to adhere to their treatment regimens most of the time. Seventy-one participants (45.2%) indicated that they had no difficulties doing what the doctor suggested they do. In contrast, only 2 (1.3%) indicated that they always experienced a difficult time doing what the doctor suggested they do. A total of 53 (34%) indicated that they were able to

do what the doctor asked them to do within the previous four weeks. Overall, participants were able to

adhere to their doctor's treatment regimens.

Table 4-4 Engagement with Healthcare Provider Instrument

Item Frequency (%) (N = 158)	Always	Usually	Sometimes	Never	No Experience
My healthcare provider…					
respects me	118 (75.2)	29 (18.5)	5 (3.2)	2 (1.3)	3 (1.9)
involves me in decisions	113 (71.5)	38 (24.1)	3 (1.9)	1 (0.6)	3 (1.9)
answers my questions	110 (66.7)	40 (24.2)	5 (3.0)	0	3 (1.9)
listens to me	106 (64.2)	43 (26.1)	5 (3.0)	1 (0.6)	3 (1.8)
respects my choices	106 (64.2)	39 (25)	6 (3.8)	1 (0.6)	4 (2.6)
engages me in my care	105 (66.5)	38 (24.1)	10 (6.3)	2 (1.3)	3 (1.9)
cares about me	105 (63.6)	38 (23.0)	11 (6.7)	1 (0.6)	3 (1.9)
provides me with information	96 (60.8)	43 (27.2)	14 (8.9)	1 (0.6)	4 (2.5)
supports my decisions	95 (60.5)	47 (29.9)	10 (6.4)	1 (0.6)	4 (2.5)
spends enough time with me	84 (53.2)	58 (36.7)	13 (8.2)	1 (0.6)	2 (1.3)
is helpful to me	83 (53.2)	57 (36.5)	11 (7.1)	2 (1.3)	3 (1.9)
deals with my problems	82 (51.9)	52 (32.9)	19 (12.0)	2 (1.3)	3 (1.9)
sees me when I ask	77 (48.7)	61 (38.6)	12 (7.6)	0	8 (5.1)

Table 4-5 Treatment adherence of persons with MS:

Medical Outcomes Study General Adherence Scale

Item Frequency (%) (N = 158)	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
I had a hard time doing what the doctor suggested I do	71 (45.2)	39 (24.8)	24 (15.3)	12 (7.6)	9 (5.7)	2 (1.3)
I followed my doctor's suggestions exactly	3 (1.9)	2 (1.3)	18 (11.5)	14 (9.0)	81 (51.9)	38 (24.4)
I found it easy to do the things my doctor suggested I do	7 (4.5)	11 (7.1)	24 (15.4)	6 (3.8)	74 (47.4)	34 (21.8)
I was unable to do what was necessary to follow my doctor's treatment plans	71 (45.5)	39 (25.0)	27 (17.3)	7 (4.5)	9 (5.8)	3 (1.9)
Generally speaking, how often in the past 4 weeks were you able to do what the doctor told you?	3 (1.9)	8 (5.1)	17 (10.9)	12 (7.7)	63 (40.4)	53 (34.0)

Frequencies for the Leeds Quality of Life Instrument are presented in Table 4-6. As expected, respondents often worried about their overall wellbeing. Over half of participants (52.2%) indicated that they have worried about their health. In contrast, 69 (43.7%) of participants felt optimistic about the future. MS is a disease that often affects family relationships. Just under half (42.4%) of participants indicated that sometimes their family relationships had been affected by MS, and 8.9% reported that their family relationships had been affected most of the time.

Table 4-6 Leeds Quality of Life Multiple Sclerosis Instrument

Item Frequency (%) ($N = 158$)	Not at all	Sometimes	Quite often	Most of the time
I have worried about other people's attitudes toward me	55 (34.8)	61 (38.6)	31 (19.6)	11 (6.7)
I have felt lonely	47 (29.7)	66 (41.8)	31 (19.6)	14 (8.9)
My health has affected my relationships with my family	46 (29.1)	67 (42.4)	31 (19.6)	14 (8.9)
I have had as much energy as usual	29 (18.4)	76 (48.1)	26 (16.5)	27 (17.1)
I have felt good about my appearance	20 (12.7)	58 (36.7)	33 (20.9)	47 (29.7)
I have felt happy about the future	17 (10.8)	69 (43.7)	37 (23.4)	35 (22.2)
I have worried about my health	13 (8.3)	82 (52.2)	41 (26.1)	21 (13.4)
I have felt tired	5 (3.2)	50 (31.8)	52 (33.1)	50 (31.8)

The Barthel Index is a commonly used measure for functional ability in individuals with MS. The Barthel Index scores for this study sample are presented in Table 4-7. The scores for this sample indicated that participants had higher levels of functioning. A total of 86.7% of participants indicated that they were able to walk greater than 50 yards independently with 69.4% able to negotiate stairs independently. This was expected given that a large portion, 77.8%, of the participants were currently in the relapsing-remitting stage of MS. Bowel and bladder dysfunction is a common occurrence with MS. Almost half (41.1%) of participants indicated that they experienced occasional urinary incontinence while 23.6% of participants indicated experiencing occasional bowel incontinence.

Table 4-7 Functional ability of persons with MS: The Barthel Index

Item (*N* = 158)	Frequency (%)
Feeding	
Needs help spreading butter, etc., or requires modified diet	16 (10.2)
Independent	141 (89.9)
Bathing	
Dependent	8 (5.1)
Independent (or in shower)	150 (94.9)
Grooming	
Needs help with personal care	5 (3.2)
Independent face/hair/teeth/shaving (implements provided)	152 (96.8)
Dressing	
Dependent	7 (4.4)
Needs help but can do about half unaided	17 (10.8)
Independent (including buttons, zips, laces, etc.)	134 (84.8)
Bowels	
Incontinent (needs to be given enemas)	6 (3.8)
Occasional accident	37 (23.6)
Continent	114 (72.6)
Bladder	
Incontinent, or catheterized and unable to manage alone	13 (8.2)
Occasional accident	65 (41.1)
Continent	80 (50.6)
Toilet Use	
Dependent	8 (5.1)
Needs some help, but can do something alone	4 (2.5)
Independent (on and off, dressing, wiping)	145 (92.4)
Transfers (bed to chair and back)	
Unable, no sitting balance	2 (1.3)
Major help (one or two people, physical), can sit	3 (1.9)
Minor help (verbal or physical)	10 (6.4)
Independent	142 (90.4)
Mobility (on level surfaces)	
Immobile or <50 yards	6 (3.8)
Wheelchair independent, including corners, >50 yards	8 (5.1)
Walks with help of one person (verbal or physical) > 50 yards	7 (4.4)
Independent (but may use any aid; for example a stick) > 50 yards	137 (86.7)
Stairs	
Unable	14 (8.9)
Needs help (verbal, physical, carrying aid)	34 (21.7)
Independent	109 (69.4)

Analysis Related to the Research Questions

The first research question for this study was: What are the relationships among patient characteristics, healthcare provider engagement, treatment adherence, functional ability, and QoL in persons with multiple sclerosis?

Relationships among patient characteristics and with the other variables were unable to be analyzed due to the lack of variability and unequal group sizes in the sample. Pearson's product-moment correlation coefficients were calculated for perceived healthcare provider engagement, treatment adherence, functional ability, and QoL. Tests for normality and homoscedasticity were performed on the data. All observations in this study were independent, and interval level data were used. The four assumptions for Pearson's product-moment correlation coefficient were met and supported the use of parametric statistical analysis.

A moderate correlation was found between perceived healthcare provider engagement and treatment adherence. A moderate correlation was also found between perceived healthcare provider engagement and QoL. Additionally, significant correlations were found between treatment adherence and QoL as well as functional ability and QoL. There were no significant differences between perceived healthcare provider engagement and functional ability ($p = .641$) or treatment adherence and functional ability ($p = .445$). The results of the correlational analysis are presented in Table 4-8.

Table 4-8 Relationships among variables using Pearson Product-Moment Correlation Coefficients (r)

	Engagement (r^2)	Treatment Adherence	Quality of Life
Treatment Adherence	.389** (.15)		
Quality of Life	.355** (.12)	.437** (.19)	
Functional Ability	.038	.061	.218* (.047)

*$p < 0.01$; **$p < .000$, Correlations: <.3 weak, .3-.4 moderate, >.4 Strong

The second research question for this study was: What are the differences between healthcare provider engagement, treatment adherence, functional ability, and QoL across the four MS disease stages of relapsing-remitting, secondary-progressive, primary-progressive, and progressive-relapsing?

The data for this research question did not meet the assumption of normality for Multiple Analysis of Variance; therefore a Kruskal-Wallis test was used with Mann-Whitney U test for post hoc analysis. To adjust for the inflated alpha wise error rate through the utilization of four statistical tests, the Bonferroni adjustment was applied yielding an adjusted a priori alpha of 0.0125. No significant difference was found

between relapsing-remitting and primary-progressive or secondary-progressive and primary-progressive status on functional ability. Significance was found related to functional ability, $\chi^2 (2, n = 147) = 6.92, p < 0.001$. Post hoc analysis revealed a difference between individuals with relapsing-remitting status ($M = 9.19, SD = 1.16$) and secondary-progressive status ($M = 7.06, SD = 2.75$) on functional ability, $U = 444, p < .000$.

Summary of Study Findings

In this chapter, the results of this descriptive correlational study were presented. The results were based on a sample size of 158 participants with MS who completed an online survey related to disease characteristics, perceived healthcare provider engagement, treatment adherence, functional ability, and QoL. Significant correlations were found between perceived healthcare provider engagement and treatment adherence. Additionally, significant correlations were found among perceived healthcare provider engagement, treatment adherence, functional ability, and QoL. A difference was found between individuals with relapsing-remitting and secondary-progressive on functional ability.

Chapter 5

Discussion

This chapter is comprised of a discussion of the results of this descriptive correlational study with links back to the literature and previous study results. The study sample characteristics will be discussed. Additionally, the results of this study will be presented within the context of the individual and social issues that are unique to persons with MS. The limitations of the study will be discussed. Finally, future implications and recommendations for further research in this area are presented.

Sample Characteristics

MS is a disease that is associated with geographical patterns. The northernmost latitudes, particularly above 40°, are known to have higher prevalence rates of MS when compared to southern latitudes (Noonan et al. 2010; Alonso & Hernan, 2008; National MS Society). MS support groups were contacted throughout the United States in an attempt to recruit a diverse sample. As a result, the sociodemographic characteristics of the sample for this study were consistent with the national estimates for individuals with MS (National MS Society, 2013).

The mean age in this study was 51 years of age. According to Hassan-Smith and Douglas (2011), the mean age of disease onset is 30 with 70% of those with MS reporting symptoms of the disease between 20 and 40 years of age. The mean age at onset of disease is consistent with this range. Disease onset is rarely reported among individuals younger than 10 and older than 60 years of age (Hassan-Smith & Douglas, 2011).

The fact that the majority of the sample was female was expected since females are two to three times more likely to have MS when compared to males (Rumrill, 2009b). Most of the subjects (83.5%) were White/Caucasian individuals, consistent with current epidemiological studies reporting that Caucasians are more likely to have MS (National MS Society, 2013). African Americans comprise a significantly smaller portion of the total population of individuals with MS, but in this study, African Americans comprised a larger percentage (14.6) of the sample than has been reported elsewhere. Weinstock-Guttman et al. (2003) studied the clinical characteristics of individuals with MS ($n = 5602$). African Americans comprised only 6% of the total sample in the study.

49

Although a large portion of the sample was in a committed relationship (defined as being either married or partnered), over a quarter were single or divorced. In a study examining racial/ethnic differences among persons with MS, Buchanan et al. (2010) reported similar demographics related to marital status. A total of 18% of Whites with MS reported being divorced or separated ($n = 29,967$) compared to 26.2% of African Americans ($n = 1,313$) (Buchanan et al., 2010), a significant difference in marital status with a larger portion of Caucasians reporting marriage when compared to African Americans. These statistics are important given the fact that social support is a key component for individuals coping with MS. MS is a disease that is best managed through high levels of social support and coping, assuming that being in a committed relationship improves social support. Physical symptoms can lead to stigma and relationship difficulties. McCabe, Stokes, and McDonald (2009) found that individuals with MS that experience a higher level of social support tend to have better coping strategies and a higher levels of QoL.

Participants in this study were highly educated with over 75% holding at least a two-year degree, including a large number who had completed graduate degrees. Marrie, Horwitz, Tyry, Campagnolo, and Vollmer (2008) found that 63.1% of participants reported a college degree ($n = 8983$) in a similar study of comorbidities among persons with MS. Education is closely linked to socioeconomic status. Income in the sample was evenly distributed across household income levels. The largest portion of participants (28.5%) reported a total annual household income greater than $100,000 per year in contrast to 20% reporting less than $40,000 per year. Participants with higher income levels may have greater access to prescribed treatments such as disease modifying medications, healthcare providers that specialize in MS management, and research studies. Buchanan et al. (2010) examined demographic characteristics through national registry data among Caucasians, African Americans, and Latinos with MS ($n = 29,967$). A total of 49.2% of Caucasians had received an evaluation at a clinic specializing in MS compared to only 36.8% of African Americans. Finally, individuals with higher socioeconomic status may have access to stress modifying therapies, such as regular exercise or diet modifications which can, in turn, improve QoL. Sung et al. (2013) examined the relationship between functional ability and health-related QoL among persons with MS. Positive correlations were found between increased physical activity, stress management, diet modification, and health-related QoL ($n = 215$) (Sung et al. 2013).

Almost all of the participants reported being told by a healthcare provider that they had MS and the majority of participants cited relapsing-remitting as their current stage of MS (77.8%). Being in the relapsing-remitting stage is associated with periods of when symptoms do not worsen and may explain the high number who reported no relapses in the previous year that required seeking medical attention. Another plausible explanation for the low number of relapses could be the use of disease-modifying therapies. Additionally, the low number of relapses could have been experienced by those individuals with the other types of MS that are not characterized by relapses. In contrast, a total of 59 participants (37.5%) reported experiencing relapses requiring medical attention in the preceding year. This total is likely composed of individuals in progressive-relapsing, those that are unsure what stage of the disease they are in, and those in relapsing-remitting.

Study participants reported a high level of perceived healthcare provider engagement. The conceptual definition for healthcare provider engagement in this research study was: A relationship with a healthcare provider that is based on information sharing, participative decision making, respect for health decisions, and management of patient concerns (Bakken et al., 2000). The aspects of healthcare provider engagement that were frequently experienced by the participants supported this definition. Respect was the most frequently experienced characteristic of engagement. A relationship that is based on mutual respect and trust is more likely to improve self-management through open dialogue (Lejbkowicz et al., 2012). This is consistent with Golla, Galushko, Pfaff, and Voltz (2011) who found that persons with MS felt that the patient-doctor relationship was enhanced if they were respected as a person and not just a patient.

Perceived Healthcare Provider Engagement

 Few studies have examined the relationship between persons with MS and their healthcare provider. No studies have examined the perceived level of engagement with their healthcare provider and treatment adherence among those with MS. One novel finding of this study is the sense of healthcare provider engagement reported by participants.

Empowering patients to be responsible for their own health through a collaborative approach is a cornerstone of patient engagement (CCM, 2013). Individualizing patient care is key to self-management among persons with chronic illness, including MS (CCM, 2013). One example is utilizing motivational interviewing to assist with personalized goal setting leading to behavior change (Lejbkowicz et al., 2012).

This is important because effective MS treatment requires lifestyle modifications through patient empowerment. Involvement in decisions and answering the patient's questions were other aspects of engagement that were experienced frequently. Increased engagement is important in order to improve the overall transfer of information and promote self-management. When healthcare providers address patient concerns in nonjudgmental ways and assess what is important to the patient, adherence and engagement are increased (Lejbkowicz et al., 2012).

Healthcare providers who engage individuals with MS can promote participative decision-making and empowerment, which may result in more positive health outcomes. An engaging relationship between the healthcare provider and person with MS can lead to increased treatment adherence (Lejbkowicz et al., 2012).

Treatment Adherence

According to the scores on the MOSGS, almost half of all participants (45.2%) experienced no difficulties doing what the doctor asked them to do. In contrast, only 5.8% of participants were unable to follow their doctor's treatment plans most of the time. Additionally, almost half of the study participants (47.4%) found it easy to follow their doctor's suggestions. Over half (51.9%) of participants indicated that they followed their doctor's suggestions exactly. Many barriers to treatment adherence have been identified related to individuals with MS. Among the most common barriers were missed injections related to disease modifying therapies, poor access to medications, the perceived lack of treatment effectiveness, and poor information related to treatment regimens (Treadaway et al., 2009).

Consistent with the findings related to healthcare provider engagement, around 60% of participants reported that their healthcare provider always provided them with information. Consistent with the relatively high income, the high level of education of the participants, and the few reported relapses, it is not surprising that 45% had no difficulties following their doctor's suggestions and almost the same number indicated that they were always able to do what the doctor told them to do. From these findings, it would seem reasonable to conclude that there may be a gap in the quality of information passed from healthcare provider to patient. The flow of information is important to ensure that the specific needs of those individuals with MS are met. Treadaway et al. (2009) examined factors related to treatment adherence among individuals with MS. In a sample of 798 persons with MS, forgetting to administer

medications (22%) and the perceived lack of benefit (16%) were among the most common reasons for non-adherence to medication regimens. Additionally, Bruce et al. (2010) discovered a strong correlation between emotional functioning and treatment adherence. Individuals with mood or anxiety disorders where five times less likely to adhere to their current medication regimen when compared to those without a mood or anxiety disorder (Bruce et al., 2010).

These findings could denote a higher level of adherence in this sample. Treadaway et al. (2009) examined self-reported adherence rates among 798 MS patients. General adherence rates were measured over three consecutive months in a multisite study. Non-adherence rates among patients with MS were reported as 39% in month one, 37% in month 2 and 36% in month three respectively (Treadaway et al. 2009). In this study, a total of 76.3% participants indicated that they followed their doctors instructions most or all of the time. In contrast, only 7.7% of participants indicated that they were unable to do what was necessary to follow their doctors treatment plan most of the time or all of the time.

There are several possible reasons for this higher level of adherence. This study was primarily comprised of individuals in relapsing-remitting stage of MS. Individuals in relapsing-remitting may be experiencing a higher level of functioning that may be associated with a higher level of adherence to treatment. Because this was a cross sectional design with all variables measured at the same time, the relationship between functional ability and treatment adherence may be bidirectional. The low number of relapses reported by participants is suggestive of a higher level of adherence. One of the goals of disease modifying therapies is to prevent the number and severity of relapses a person experiences over time. Preventing the number of relapses by an increased level of adherence could ultimately improve QoL.

Functional Ability

The Barthel Index was used to measure functional ability in this study. The scores reflected a high functioning sample of individuals with MS with respect to physical abilities. Almost 70% of participants indicated independence with physical ambulation such as walking stairs and the majority also reported independence with daily self-care and toilet use. However, almost half of the participants reported some degree of bowel and bladder dysfunction, including occasional or frequent incontinence of bladder and bowel. These data were consistent with the disease stages identified in this sample. The sample was comprised of a high percentage of those individuals in relapsing-remitting. These individuals were more

likely to experience a higher level of physical functioning in contrast to those in primary-progressive and secondary-progressive. Ultimately, these physical symptoms can have a disruptive effect on QoL by inhibiting an individual's ability to function normally.

<div align="center">Quality of Life</div>

QoL as defined in this study is an overall state of wellbeing as perceived by the individual with MS (Forbes et al., 2006). QoL is often overlooked and considered an unmet need in the routine management of care in those with MS (Gurwell & Berger, 2012).

Participants indicated an overall high quality of life, but less than 30% indicated that their MS did not affect their relationships with their families. In contrast, about 30% indicated that their MS affected their relationships with their families at least quite often. This is consistent with previous literature examining social relationships among those with MS. McCabe et al. (2009) examined social support among individuals with MS and found that those individuals with increased social support have higher QoL (n = 382). Although, in this study, social support was not directly measured, one item about loneliness on the Leeds QoL Instrument is an indirect measure of social support. A total of 29.7% of participants indicated that they never felt lonely which may be suggestive of an increased level of social support.

A lack of energy may be a result of disease processes, medications, depression, or some combination thereof. Fatigue seemed to vary across time with almost half indicating that they sometimes had as much energy as usual while almost 20% indicated that they did not have as much energy as usual. This was expected given the high prevalence of fatigue and depression associated with MS. Previous studies have reported depression rates among those with MS as high as 40% (Wood et al., 2013).

The first research question for this study was: What are the relationships among patient characteristics, disease type and stage, healthcare provider engagement, treatment adherence, functional ability, and QoL in persons with multiple sclerosis? Discussion about the findings related to the first research question will follow in subsequent sections.

<div align="center">Functional Ability and Treatment Adherence</div>

The findings in this study did not support a relationship between functional ability and treatment adherence. This could be due to the highly variable disease progression associated with MS. Each individual with MS experiences a unique disease progression. The majority of participants in this study

were high functioning so there was less variability in the data, which may have attenuated any relationship. Since participants were already high functioning, they may not have viewed their treatment adherence as a positive influence on their ability to function daily.

Additionally, the lack of a relationship between functional ability and treatment adherence could be related to the use of disease modifying therapies (DMT). DMT's reduce the number of relapses a person with MS experience but are less effective in slowing the overall progression of the disease (Willbanks, 2012). Some participants may not have elected to use DMT's given that some have significant side effects. This could explain the disparity between treatment adherence and functional ability.

Treatment Adherence and QoL

In contrast to poor adherence in previous studies, treatment adherence in this sample was high with 74.4% of participants indicated that they were able to do what the doctor asked them to do most or all of the time. A positive correlation was found in this study between treatment adherence and QoL. MS is a complex disease that can negatively influence QoL. A number of issues such as physical symptoms, emotional stressors, cognitive alterations, and social isolation often work synergistically to decrease QoL (Bruce et al., 2010). Together, these symptoms can interfere with an individual's ability to maintain employment, nurture relationships, pursue leisure activities, and live a fulfilling life. Treatment regimens must be broad and comprehensive in order to address the myriad issues surrounding MS. Often treatment regimens focus on symptom management and overlook other factors that negatively influence QoL (Gurwell & Berger, 2012). Treatment adherence is a key aspect in QoL among those with MS. Poor treatment adherence among those with MS has been reported in previous literature (Klaur & Zettl, 2008b; Ross, 2008; Bruce et al., 2010).

Additional factors related to adherence and QoL may be derived from the demographic characteristics of this sample. The sample was primarily comprised of White females. Most participants were married with almost 30% reporting an annual household income greater than $100,000. Individuals in this income level may be more likely to be employed with fulfilling careers. In a study of socioeconomic status and comorbidities related to with MS, Marrie et al. (2008) found that the odds of comorbidities decreased with an annual income greater than $100,000. Moreover, the odds of comorbidities decrease as education level increased (Marrie et al., 2008). Education level is an important component to related to

overall QoL and MS. Yamout et al. (2013) examined QoL among persons with MS and found that unemployment was negatively associated with QoL ($n = 201$). Moreover, individuals that were married may experience a higher level of social support and be able to mobilize effective coping strategies. Individuals with poor social support were less likely to use effective coping strategies and ultimately experience a poor QoL (McCabe et al., 2009).

Overall, the sample in this study reflected a higher level of treatment adherence and a positive correlation with QoL. Several factors such as higher income and education level may have increased adherence and ultimately QoL. Additionally, access to recommended treatment regimens and stress reducing activities such as exercise may have been more readily available in this population.

Perceived Healthcare Provider Engagement and Functional Ability

In this study no relationship was noted between perceived healthcare provider engagement and functional ability. This could be due to the highly variable, but progressive decline in functional ability over the course of the disease progression associated with MS. Each person with MS experiences a unique progression characterized by the different disease stages. Additionally, persons with MS may not view their healthcare provider as having a direct influence on their functional ability. A person's ability to function on a day-to-day basis may be more associated with the medications used in treatment regimens. Treatment regimens can greatly affect the functional ability of the person with MS. A person's ability to follow the recommended treatment regimens provided by their healthcare provider may affect their functional ability. In this study, however, most participants indicated that they were able to follow their healthcare providers recommendations without difficulty.

Perceived Healthcare Provider Engagement and Treatment Adherence

In the current study, the positive relationships between healthcare provider engagement and treatment adherence could suggest an effective reciprocal flow of information between healthcare provider and patient. This improved flow of information may be represented through productive interactions and ultimately an improved QoL. Lejbkowicz et al. (2012) described a model of healthcare delivery for persons with MS that was based on empowerment, participative decision-making, information sharing, and personalized care. Since MS is a disease that affects everyone differently, care must be personalized in order to provide the greatest benefit. Individuals with MS are often faced with challenges related to

community, healthcare delivery systems, and lifestyle changes. A strong sense of engagement is necessary to facilitate treatment adherence and to improve overall health outcomes. Lejbkowicz et al. (2012) describes this type of healthcare delivery as disease-management programs that are based on patient contributions.

<div align="center">Perceived Healthcare Provider Engagement and QoL</div>

Individuals with MS often experience a change in QoL due to the multifaceted effects of the disease. Physical symptoms along with social and cognitive dysfunction often negatively affect QoL in persons with MS. Treatment to improve QoL related to MS often focuses on symptom management and lifestyle changes (Gurwell & Berger, 2012; McCabe et al., 2009; Miller & Allen, 2010). In this study a positive correlation was found between perceived healthcare provider engagement and QoL among persons with MS. Although no known studies have focused specifically on the concepts of perceived healthcare provider engagement and QoL in this population, these study findings are evidence that as healthcare provider engagement increases so does QoL.

A high level of perceived healthcare provider engagement could benefit those with MS because important individual and social issues are addressed more thoroughly. Forbes, While and Taylor (2007) examined the most important unmet needs among 445 individuals with MS. Among the most important unmet needs identified was the desire for improved support from their healthcare provider (Forbes et al., 2007). Those individuals that are more engaged with their healthcare provider may feel more inclined to discuss sensitive issues such as bowel and bladder control or feelings of depression (White, White, & Russell, 2007). This could ultimately lead to a more comprehensive treatment regimen and participative decision-making (Lejbkowicz et al., 2012). A higher level of perceived engagement could also lead to a greater sense of empowerment for persons with MS. Feelings of loss of control are inevitable given that MS is a disease that affects physical, psychosocial, and cognitive function. A more engaging relationship with the healthcare provider focusing on personalized care could lead to more collaborative efforts to address such complex issues (White, White, & Russell, 2007). This sense of empowerment could ultimately lead to an overall improved treatment regimen and overall wellbeing through the management of physical, emotional, and social issues associated with MS (Lejbkowicz et al., 2012). This is consistent with previous studies examining health related QoL in persons with MS. According to Miller and Allen (2010),

<div align="center">57</div>

incorporating the patient's perspective was an essential component to improve outcomes and overall wellbeing in those with MS. Moreover, assessing health related QoL among those with MS can lead to a greater sense of self-awareness and ultimately an increased level of control over cognitive and symptom management (Bruce & Allen, 2010; Gerwell & Berger, 2012).

<div align="center">Differences across Disease Stages</div>

The second research question for this study was: What are the differences in perceived healthcare provider engagement, treatment adherence, functional ability, and quality of life across the four MS disease stages of relapsing-remitting, secondary-progressive, primary-progressive, and progressive-relapsing?

A significant difference was found between relapsing-remitting and secondary-progressive MS on functional ability. This is an expected finding since secondary-progress MS is characterized by less frequent relapses with a steady decline in overall functional ability (MS Society, 2013). Once diagnosed, 50% of individuals with relapsing-remitting MS will convert to secondary-progressive MS within 10 years (MS Society, 2013). The mean age of participants in this study was 51 with most reporting first symptoms 10 to 69 years of age ($M = 35.2$). Participants reporting a greater degree of functional decline may be those individuals that have been living longer with the disease.

No significant differences were found between relapsing-remitting and primary-progressive MS on functional ability. Additionally, no significant differences were found between secondary progressive and primary-progressive on functional ability. This could be related to the lack of variability and small sample size within the different subgroups of MS.

Findings Compared to The Chronic Care Model

The findings of this study were consistent with the Chronic Care Model (The Chronic Care Model [CCM], 2013). One underlying tenet of CCM is to empower the individual to take an active role in their health. Persons with chronic disease function within the community and healthcare system simultaneously. Improving health literacy, patient safety, and cultural competency are central to CCM.

According to the CCM (2013), healthcare delivery that is based on enhanced communication provides the basis for active participation by an individual with chronic disease. A proactive approach to healthcare delivery is the key to effective long-term therapy for those individuals with chronic disease (CCM, 2013). The positive relationships between healthcare provider engagement, QoL, and treatment adherence found in this study are consistent with the CCM. Addressing the diverse needs of those individuals with MS could be achieved by increasing the perceived healthcare provider engagement. This is especially important for those individuals with MS because the complexity of the disease requires a broad range of behavioral and lifestyle changes. Individuals with MS that experience a high level of perceived healthcare provider engagement may have a greater sense of support (Lejbkowicz et al., 2012). An increased sense of support can lead to productive interactions with their healthcare provider and improve treatment adherence, functional ability and overall QoL. Based on the findings of this study, a revised version of the adapted CCM was developed (Figure 5-1).

QoL among persons with MS shares a relationship with perceived healthcare provider engagement and treatment adherence. Functional ability, however, is not related to perceived healthcare provider engagement or treatment adherence but is positively related to QoL.

Overall, this study supported the central components of CCM (CCM, 2013). Individuals with MS experience diverse changes in physical, emotional, and cognitive function. Improving information sharing within the community and healthcare system is important to ensure an improved QoL for persons with chronic disease. A health delivery system that is based on a high level of perceived engagement could improve a sense of QoL among those individuals with MS.
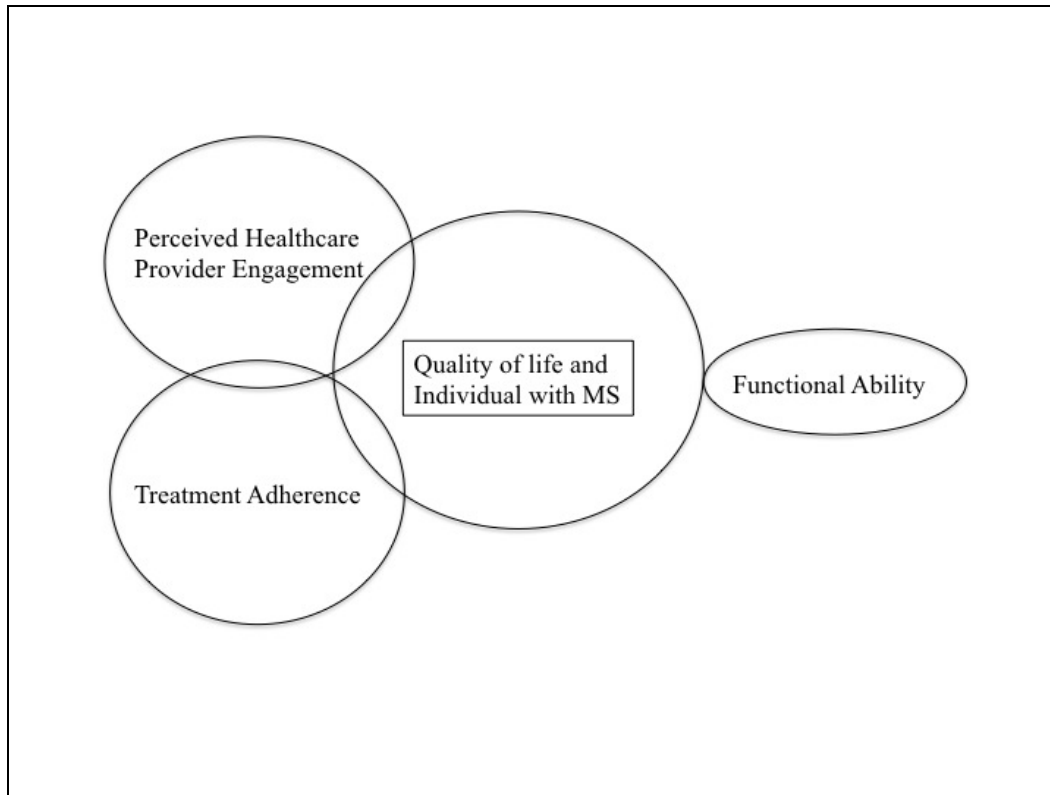
Figure 5-1 Revised adapted chronic care model

Limitations

The major limitation of the study methods was the exclusive use of self-report and the potential for social desirability to affect participants' responses. Social desirability is the tendency of an individual to project a more positive image of themselves when answering social-based measures (Waltz, Strickland, & Lenz, 2010). The measures in this study may be susceptible to social desirability responses because some items may be viewed as invasive or more socially desirable than others. The sample in this study consisted of individuals with higher education levels and socioeconomic status. Individuals may have felt more compelled to answer questions in a more positive manner. The use of anonymity in this study, however, helps to reduce the possibility of social desirability (Waltz, Strickland, & Lenz, 2010).

In this study, participants self-reported their stage and diagnosis of MS. The use of self-report, however, was an economical way to obtain data from a geographically distributed sample in the

community. Obtaining subjects through providers' offices or clinics could have resulted in a skewed sample of only persons who were ill.

Because this was an online survey, only individuals with access to a computer were able to participate. The use of online-based data collection may be linked to the high-income level of the sample, with the more educated and wealthier individuals having increased access to computers. Sampling online, rather than in clinical settings, however, may have increased the confidence of participants that their responses were not going to be shared with their providers. Additionally, online sampling had the potential to recruit participants who are not under clinical care or seek care infrequently. This decreases the chance of socially desirable responses on the questionnaire.

The sample for this study was more homogeneous than desired. Even though there was an attempt to gain a heterogeneous population by contacting MS groups in a broad pattern across the United States, there is no way of knowing if the majority of the participants were from one region. The sample for this study was not a diverse sample. However, the demographic characteristics of the sample were consistent with the target population of individuals 18 years or older with a diagnosis of MS. An additional limitation of this study was the inability of participants to elaborate on specific questions within the questionnaire.

Implications for the Practice of Healthcare Providers

The most important finding in this study was the linking of perceived healthcare provider engagement and QoL. A healthcare provider/patient relationship that is based on mutual respect and collaborative decision-making is important to ensure effective health outcomes and improve overall QoL (Lejbkowicz et al., 2012; CCM, 2013). MS is a complex disease that requires a multidisciplinary approach to disease management. In a study examining the perceived unmet needs among 497 individuals with MS, Lorefice et al. (2013) found that 30% expressed the desire for a multidisciplinary approach to their care. This study highlighted the importance of how a sense of perceived healthcare provider engagement and communication affect the overall quality of life among individuals with MS. Effective management of such a complex disease requires intraprofessional collaboration as a primary model of care to decrease the overall disease impact and increase QoL (Lorefice et al., 2013).

Implications for Nursing Practice

Given the shift in healthcare from hospitals to community-based programs, this study has important implications for nursing practice (healthcare.gov, 2013). The results of this study support the use of intraprofessional collaboration in patient-centered community-based programs to establish or improve the relationship among those with chronic disease and their healthcare providers (healthcare.gov, 2013). Further research is needed to understand what factors within the healthcare provider and patient relationship would have the greatest influence on a positive health outcome among those with MS.

This study supports the importance of a strong healthcare provider/patient relationship to ensure treatment adherence and QoL. Individuals with MS are increasingly vulnerable and require accurate information to improve their overall QoL (Lorefice et al., 2013). Nursing's role as a primary educator of those with chronic disease can greatly influence the flow of information and health services (Brodkey et al., 2011). Nursing is well positioned to provide community-based healthcare for persons with chronic diseases such as MS. For example, nurses teaching classes in community centers focusing on topics relating to the management of MS could be a vital component in promoting effective engagement with healthcare providers. Nurses serving as liaisons between individuals with MS and their healthcare providers could strengthen communication and information sharing. Additionally, nurses could facilitate the transfer of information by suggesting reputable sources such as the National MS Society or social media based websites such as PatientsLikeMe ™. This, in turn, could lead to greater treatment adherence and improved QoL for those with MS. Nursing could play a pivotal role in fostering productive interactions between patients with chronic diseases and their healthcare providers.

Recommendations for Future Research

Future research using regression models could allow identification of predictive relationships of treatment adherence, quality of life, and functioning on the dependent variable of overall QoL among persons with MS. Identifying and targeting such factors could serve as the basis for educational programs for healthcare providers caring for those with MS. Further research is also needed to gain a greater understanding of what specific factors increase the transfer of quality information from healthcare provider to patient. Identifying and addressing these factors could assist healthcare providers to improve outcomes for those with MS through personalized treatment regimens. Accurate information is important for those

with MS to ensure that effective lifestyle modifications including dietary changes and exercise in order to improve QoL.

Intraprofessional collaboration is essential for the effective treatment of MS (Lorefice et al., 2013). The combined strength of collaboration ensures that treatment regimens are empirically based and offers effective disease management for individuals with MS. The complexity of MS treatment requires such collaboration to foster patient-centered care for the positive health outcomes.

Additionally, future research could examine the specific subgroups of MS disease stages to determine if there is a difference in factors affecting QoL at different stages. Each stage of MS requires differing levels of care. Personalizing healthcare specific to the stage of MS ensures that needs are identified and addressed.

Further research can identify the unmet needs of individuals with MS and can guide treatment through collaborative efforts. Ensuring that individuals with MS and other chronic diseases have personalized treatment regimens is essential for high quality patient-centered care.

Summary

 This study explored the relationships among disease characteristics, perceived healthcare provider engagement, treatment adherence, functional ability, and QoL in persons with MS. Positive correlations were found between perceived healthcare provider engagement, treatment adherence, and QoL. Additional positive correlations were found between functional ability and QoL.

The complex nature of MS requires strong relationships between healthcare providers, support systems, and community to ensure a high QoL. This study highlights the importance of such relationships and their influence on the QoL among persons with MS. In the future, more research is needed to determine the best approach strengthen links between the persons with MS, the healthcare system, and community to ensure productive interactions that improve overall health outcomes. Although predictable, the findings in this study are important by setting the foundation for future research to improve QoL for all individuals with MS.

Appendix A

Permission to Use Chronic Care Model

WAECP1418427

February 23, 2014

Brian Holland
University of Texas Arlington College of Nursing

Dear Mr. Holland;

Thank you for your request to disertation the following from *Effective Clinical Practice:*

Figure;Wagner EH, Chronic Disease Management: What Will It Take to Improve Care for Chronic Illness? Effective Clinical Practice, 1998, Vol1

Permission is granted to print the preceding material with the understanding that you will give appropriate credit to *Effective Clinical Practice* as the original source of the material. Any translated version must carry a disclaimer stating that the American College of Physicians is not responsible for the accuracy of the translation. This permission grants non-exclusive, worldwide rights for this edition in disertation for not for profit only. ACP does not grant permission to reproduce entire articles or chapters on the Internet unless explicit permission is given. This letter represents the agreement between ACP and Brian Holland for request WAECP1418427 and supersedes all prior terms from the requestor. The Annals of Internal Medicine wants to encourage users to go to the original article on the website for scientific integrity, in the event there are retractions and corrections.

Thank you for your interest in Annals of Internal Medicine. If you have any further questions or would like to discuss the matter further, please contact me at 856-489-8555 or fax 856-489-4449.

Sincerely,

Gina Brown
Permissions Coordinator

Appendix B

Engagement with Health Care Provider Instrument

Engagement with Health Care Provider

Your primary health care provider is probably your doctor. However, your health care provider might also be a nurse, nurse practitioner or physician's assistant.

Please check the type of health care provider that you see on a regular basis and then complete this page with that person in mind.

My primary health care provider is (please check one):

_____ Doctor
_____ Nurse
_____ Nurse Practitioner
_____ Physician Assistant
_____ Other, please describe: _____

Please rate the degree to which each statement is true for you:

1= Always   2= Usually   3=Sometimes   4= Never   n/a= no experience

Always	Usually	Sometimes	Never	No Experience	My health care provider:
1	2	3	4	n/a	Listens to me
1	2	3	4	n/a	Cares about me
1	2	3	4	n/a	Answers my questions
1	2	3	4	n/a	Spends enough time with me
1	2	3	4	n/a	Involves me in decisions
1	2	3	4	n/a	Respects my choices
1	2	3	4	n/a	Deals with my problems
1	2	3	4	n/a	Engages me in my care
1	2	3	4	n/a	Is helpful to me
1	2	3	4	n/a	Respects me
1	2	3	4	n/a	Supports my decisions
1	2	3	4	n/a	Sees me when I ask
1	2	3	4	n/a	Provides me with information

67

Appendix C

Permission to use Engagement with Healthcare Provider Instrument

Dr. Bakken,

I am a PhD student at the University of Texas at Arlington and I am seeking permission to use the Engagement with Healthcare Provider Instrument in my dissertation. My focus is the relationship between healthcare provider engagement, treatment adherence, and functional ability among persons with multiple sclerosis. Did you develop the engagement instrument? If not, could you please direct me to someone that be able might give me permission to use it?

Thank you,

Brian Holland, MSN, RN

Yes, I was one of the developers. Feel free to you it.

Suzanne Bakken, RN, PhD, FAAN, FACMI
The Alumni Professor of Nursing and Professor of Biomedical Informatics
Director, Center for Evidence-based Practice in the Underserved
Director, Reducing Health Disparities Through Informatics Pre- and Post-doctoral Training Program
Principal Investigator, Washington Heights Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER)
Co-Director, Biomedical Informatics Resource, Irving Institute for Clinical and Translational Science

For more about my grants and publications see Columbia University Scientific Profiles:
http://irvinginstitute.columbia.edu/cusp/cgi-bin/ww2ui.cgi/test?wwid=275D44A8-C7B0-11DD-8DD8-DEAA26ABADBC

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Appendix D

Medical Outcomes Study General Adherence Instrument

Table 1: Medical Outcomes Study General Adherence Items

How often was each of the following statements true for you during the past 4 weeks?

(Circle One Number on Each Line)

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1. I had a hard time doing what the doctor suggested I do ...	1	2	3	4	5	6
2. I followed my doctor's suggestions exactly ...	1	2	3	4	5	6
3. I was unable to do what was necessary to follow my doctor's treatment plans ...	1	2	3	4	5	6
4. I found it easy to do the things my doctor suggested I do ...	1	2	3	4	5	6

5. Generally speaking, how often during the past 4 weeks were you able to do what the doctor told you?

(Circle One)

None of the time............................. 1
A little of the time........................... 2
Some of the time 3
A good bit of the time..................... 4
Most of the time............................. 5
All of the time................................. 6

Appendix E

Rand Medical Outcome Study: Public Domain Documentation

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Measures of Patient Adherence: RAND Medical Outcomes Study

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The Medical Outcomes Study was a two-year study of patients with chronic conditions. As part of the study, the research team assessed how well patients adhered to treatment regimes.

The measures of patient adherence include two types of measures. A general measure assessed patients' adherence to treatment for heart disease, diabetes, and hypertension; a specific measure assessed patients' adherence to treatment recommendations for the tracer conditions studied in the MOS and also gathered information about how often the patient carried out the recommendations.

Available Documents

Permissions Information

All of the surveys from RAND Health are public documents, available without charge.

Translations

Many of the surveys listed are available in other languages. If you are interested in translating any surveys into another language, see our translation guidelines.

Questions or Comments?

Email us at RAND_Health@rand.org

of Life — 1995

igned to be a companion to the

e of the Medical Outcomes Trust.

Permissions Information

All of the surveys from RAND Health are public documents, available without charge.

Translations

Many of the surveys listed are available in other languages. If you are interested in translating any surveys into another language, see our translation guidelines.

Questions or Comments?

Email us at RAND_Health@rand.org

Appendix F

The Barthel Index

**THE
BARTHEL
INDEX**

Patient Name: _____

Rater Name: _____

Date: _____

Activity	Score

FEEDING
   0 = unable
   5 = needs help cutting, spreading butter, etc., or requires modified diet
   10 = independent   _____

BATHING
   0 = dependent
   5 = independent (or in shower)   _____

GROOMING
   0 = needs to help with personal care
   5 = independent face/hair/teeth/shaving (implements provided)   _____

DRESSING
   0 = dependent
   5 = needs help but can do about half unaided
   10 = independent (including buttons, zips, laces, etc.)   _____

BOWELS
   0 = incontinent (or needs to be given enemas)
   5 = occasional accident
   10 = continent   _____

BLADDER
   0 = incontinent, or catheterized and unable to manage alone
   5 = occasional accident
   10 = continent   _____

TOILET USE
   0 = dependent
   5 = needs some help, but can do something alone
   10 = independent (on and off, dressing, wiping)   _____

TRANSFERS (BED TO CHAIR AND BACK)
   0 = unable, no sitting balance
   5 = major help (one or two people, physical), can sit
   10 = minor help (verbal or physical)
   15 = independent   _____

MOBILITY (ON LEVEL SURFACES)
   0 = immobile or < 50 yards
   5 = wheelchair independent, including corners, > 50 yards
   10 = walks with help of one person (verbal or physical) > 50 yards
   15 = independent (but may use any aid; for example, stick) > 50 yards   _____

STAIRS
   0 = unable
   5 = needs help (verbal, physical, carrying aid)
   10 = independent   _____

                                       TOTAL (0–100): _____

Appendix G

Permission to Use The Barthel Index

Dear Brian,

Thank you for emailing us your User Agreement. May I take this opportunity to remind you that I must also receive the signed original version by post.

As you are carrying out a not-funded research, I am pleased to be able to send you the US-English version of the BI

I have also attached the scoring manual for your analysis. Please confirm safe reception.
Furthermore in case of E-application, please follow the conditions mentioned in the User Agreement.

We wish you all the best in your study. Please do not hesitate to get in touch if you have any questions.

Come to the Mapi Booth (#38) at the ICPE Conference (August 25-28, 2013, Montreal) to discover the new features of the Post-Marketing Requirements (PMR) database !

New instrument distributed by Mapi Research Trust for the Cincinnati Children's Hospital Medical Center & James P. Franciosi (USA): PEESS V2.0 (Pediatric Eosinophilic Esophagitis Symptom Severity Module, Version 2.0)

New! It is now possible to pay your invoice online with a credit card(except for American Express) It is quick, easy and secure. Don't hesitate to ask me should you be interested.

Best regards,
Sunita Shetty
(Not in the office on Wednesday mornings)
Information Resources Specialist
PROs & ClinROs Information Support Unit

Mapi Research Trust
27 RUE DE LA VILLETTE | 69003 LYON | FRANCE
Tel.: +33 (0)4 27 44 58 61 (Direct line)| Fax: +33 (0) 4 72 13 66 82
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Appendix H

Leeds Multiple Sclerosis-QoL Questionnaire

LMS-QoL

Name:_____ Age:_____ Sex:_____

On the following pages you will find some statements which have been made by people who have Multiple Sclerosis

Instructions: This questionnaire consists of 8 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling **During the past month**. Circle the appropriate number.

1. **My health has affected my relationships with my family**
   0 Not at all
   1 Sometimes
   2 Quite often
   3 Most of the time

2. **I have felt lonely**
   0 Not at all
   1 Sometimes
   2 Quite often
   3 Most of the time

3. **I have felt good about my appearance**
   3 Not at all
   2 Sometimes
   1 Quite often
   0 Most of the time

4. **I have worried about my health**
   0 Not at all
   1 Sometimes
   2 Quite often
   3 Most of the time

5. **I have worried about other people's attitudes towards me**
   0 Not at all
   1 Sometimes
   2 Quite often
   3 Most of the time

6. **I have felt tired**
   0 Not at all
   1 Sometimes
   2 Quite often
   3 Most of the time

7. **I have had as much energy as usual**
   3 Not at all
   2 Sometimes
   1 Quite often
   0 Most of the time

8. **I have felt happy about the future**
   3 Not at all
   2 Sometimes
   1 Quite often
   0 Most of the time

_____ Subtotal Page 1

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79

Appendix I

Permission to Use the Leeds Multiple Sclerosis Quality of Life Questionnaire

UNIVERSITY OF LEEDS

Dear LMSQoL User:

With this letter The University of Leeds is pleased to grant you permission to use the Leeds Multiple Sclerosis Quality of Life Questionnaire (LMSQoL) for non-commercial purposes. In this instance, non-commercial purposes means that you agree not to use the LMSQoL in research or other work performed for a third party, funded by a commercial third party (e.g. clinical trial) or provide the questionnaire to a third party.

When reproducing the LMSQoL, please include an identifier as follows:

> Leeds Multiple Sclerosis Quality of Life Questionnaire, © 2001,
> The University of Leeds; All rights reserved

For purposes of standardization of content, scoring and labelling, we wish to assure users of the questionnaire and interpreters of its results that the designation "LMSQoL" refers to the identical instrument and scoring in all cases. This allows comparison of scores across projects and applications.

Therefore, if you add questions to or delete questions from the LMSQoL; or embed it into a larger questionnaire; or modify its layout or order of questions, please give the modified questionnaire its own name and indicate the following on the questionnaire form, including at its end:

> Questionnaire includes portions of the Leeds Multiple Sclerosis Quality of Life Questionnaire
> (items number--), © 2001, The University of Leeds;
> All rights reserved

It is not permitted to create a non-English language version or culturally-modified version of the RA-WIS without explicit prior permission, which will also require following an agreed adaptation protocol. For existing language versions see the web site at:

http://www.leeds.ac.uk/medicine/rehabmed/psychometric/Scales1.htm
In return for royalty free permission to use the LMSQoL, we request that:

a. you complete and return The University of Leeds User's Profile form describing the nature of the project in which you plan to use the LMSQoL; and

In addition if you intend to use the RA-WIS in a research study we request that

b. you make available to The University of Leeds non-identifiable data from your study which may allow it's research group to refine the applicability, precision and standardization of scoring of the LMSQoL; and

c. the study data not be used to develop another questionnaire with the same purpose as the LMSQoL.

If you agree to the terms of this letter of permission to use the LMS-QoL, please return a signed copy for my attention along with the completed User's Profile Form, and I will email you a copy of the LMS-QoL.

(Scale scoring guidance notes will also be included).

For technical advice and consultation regarding the use of the LMSQoL, please contact Professor Alan Tennant, at The University of Leeds a.tennant@leeds.ac.uk

Respectfully,
LMSQoL Administrative Manager

Agreed to by:

_____
Signature

PhD student, University of Texas at Arlington

_____
Title/organisation

Please complete and return this form to LMS-QoL Administrative Manager, The University of Leeds, Academic Department of Rehabilitation Medicine, D Floor, Martin Wing, Leeds General Infirmary, Leeds, England, LS1 3EX. Fax: 0113 3922559. Email: V.E.Lane@leeds.ac.uk

LMS-QoL

User Profile
(Please type or print clearly)

Please complete and return this form to LMS-QoL Administrative Manager, The University of Leeds, Academic Department of Rehabilitation Medicine, D Floor, Martin Wing, Leeds General Infirmary, Leeds, England, LS1 3EX. Fax: 0113 3922559. Email: V.E.Lane@leeds.ac.uk

Principal Investigators/Project Directors Name: Brian Holland
Organisation/Department: University of Texas at Arlington College of Nursing
Street Address: 701 S. Nedderman Dr.
City: Alrlington   County/State: TX   Postcode/Zip: 76019
Country: USA   E-mail: brian.holland@mavs.uta.edu
Telephone: 817-272-2011   Fax: 817-272-5006

Organisation Type
Indicate by placing a 'X' in the box next to the category that best describes the type or primary purpose of your organization

	Primary Care Group		NHS Hospital Trust		Insurance Company/Health Plan
X	University/College		Charity		Pharmaceutical Company
	Government Agency		Other NHS		Other:_____

If you propose to use the MS-QoL as a Clinical Screening Tool Only (IE. Not for research purposes) please tick this box and ignore the remaining questions	

Briefly describe the project(s) for which you plan to use the LMS-QoL (indicate aims, design and key sample characteristics):
I am a PhD student currently beginning dissertation. I plan to examine the relationship between treatment adherence, healthcare provider engagement, functional ability, and quality of life among persons with multiple sclerosis. Quality of life will be my outcome variable and I plan to use the Leeds MS QOL scale as a primary measure of the outcome variable.
Project sample size: 150 adults with multiple sclerosis
Projects duration: 6 months
Methods of measurement (e.g. Mail survey): Internet based survey
Other measurement tools included (e.g. SF-36):

Appendix J

Multiple Sclerosis Quality of Life Questionnaire

Multiple Sclerosis Quality of Life Survey

RESEARCHER: Brian Holland, PhD student, RN
RESEARCHER SUPERVISOR: Dr. Jennifer Gray, PhD, RN

TITLE OF PROJECT: Factors Affecting Quality of Life in Persons with Multiple Sclerosis This survey is for individuals 18 years or older with a diagnosis of multiple sclerosis. You are invited to take part in this research survey. The researcher is a doctoral student at The University of Texas at Arlington, College of Nursing. The information in this form describes what you will do for this study. If you have any questions about this survey, or you do not understand anything in this form, you are asked to contact the researcher.

WHAT IS THIS STUDY ABOUT? This study is being done in order to improve care for persons living with multiple sclerosis. More information is needed to better understand your perspective on how the disease affects your life, your treatment, and what you need from your healthcare provider.

HOW LONG WILL THIS STUDY LAST? It will take approximately 10 to 15 minutes to complete this survey.

PROCEDURE As a participant you will read this consent form and if you agree to participate you will complete a survey on personal information about yourself such as age, education, illness. This survey will also ask questions about your relationship with your healthcare provider, treatment, functional ability, and quality of life. No information will be collected that will result in identifying you. You may discontinue participation at any time without penalty.

HOW MANY PEOPLE WILL BE IN THIS STUDY? It is anticipated that there will be 200 people in this study.

WHAT WILL YOU GAIN FROM THIS STUDY? You will not be paid for participating in this study. Although you may not benefit directly from this study, your participation in this study may help other patients with multiple sclerosis.

IS THERE POSSIBLE RISKS/DISCOMFORT FROM DOING THIS STUDY? There are no foreseeable risks and/discomforts from doing this study. If, however, you are uncomfortable and unable to continue with the questionnaires, you can discontinue the study at any time.

WHO IS PAYING FOR THIS STUDY? This study is funded by the researcher.

IS MY PARTICIPATION VOLUNTARY? Your participation in this research study is voluntary and you have a right not to participate or stop at any time without any penalty.

WILL MY CONFIDENTIALITY BE PROTECTED? Every attempt will be made to see that your study results are kept confidential. Your personal information will not be linked to the survey answers that you provide. All data collected from this study will be stored on a secure server at the University of Texas at Arlington for at least three (3) years after the end of this research. The results of this study may be published and/or presented at meetings without naming you as a participant. Additional research studies could evolve from the information you have provided, but your information will not be linked to you in anyway; it will be anonymous. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA Institutional Review Board (IRB), and personnel particular to this research have access to the study records. Your records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above. The IRB at UTA has reviewed and approved this study and the information within this consent form. If in the unlikely event it becomes necessary for the Institutional Review Board to review your research records, the University of Texas at Arlington will protect the confidentiality of those records to the extent permitted by law.

DO YOU WANT TO BE IN THIS STUDY? You understand that by continuing this survey, you have chosen to be a part of this study and you have read this consent. You understand the information, and can ask questions about this study. You are 18 years of age or older and voluntarily agree to be in this study. You understand that you can stop participating in the study by exiting the survey or by closing the browser window. You understand that you will not be able to withdraw from the survey after submitting your completed survey. As the Researcher of this study, I have explained the purpose, the procedures, the benefits, and the risks that are involved in this research study.

CONTACT FOR QUESTIONS Questions about this research study may be directed to the researcher, Brian Holland at 806-577-7246 or by email brian.holland@mavs.uta.edu. You may also contact my Faculty advisor, Dr. Jennifer Gray at 817- 272-2776 or by email jgray@uta.edu. Any questions you may have about your rights as a research participant or a research-related injury may be directed to the Office of Research Administration; Regulatory Services at 817-272-2105 or regulatoryservices@uta.edu.

I consent to participate in this study
❍   Yes
❍   No

What is your gender?
❍   Male
❍   Female

Are you Hispanic?
❍   Yes
❍   No

What is your primary race?
❍   White/Caucasian
❍   African American
❍   Asian
❍   Native American
❍   Pacific Islander
❍   multiple races

What is your age?
_____

What is your martial status?
❍   Married
❍   Divorced
❍   Partnered
❍   Single
❍   Widow/widower

What is your combined annual household income?
❍   Less than 30,000
❍   30,000 – 39,999
❍   40,000 – 49,999
❍   50,000 – 59,999
❍   60,000 – 69,999
❍   70,000 – 79,999
❍   80,000 – 89,999
❍   90,000 – 99,999
❍   100,000 or more

What is the highest level of education you have completed?
- ○ Less than High School
- ○ High School / GED
- ○ Some College
- ○ 2-year College Degree
- ○ 4-year College Degree
- ○ Masters Degree
- ○ Doctoral Degree

Have you been told by a healthcare provider that you have multiple sclerosis?
- ○ Yes
- ○ No

At what age did you first notice symptoms of multiple sclerosis?

What type of multiple sclerosis do you have?
- ○ Relapsing-Remitting
- ○ Secondary-Progressive
- ○ Primary-Progressive
- ○ Progressive-Relapsing
- ○ Unsure

In the past year, how often have you had a relapse in your multiple sclerosis causing you to seek medical attention?
- ○ 0
- ○ 1 to 2
- ○ 3 to 4
- ○ greater than 4

Please check the type of health care provider that you see on a regular basis and then complete this page with that person in mindMy primary healthcare provider is a
- ○ Doctor
- ○ Nurse
- ○ Nurse Practitioner
- ○ Physicians Assistant
- ○ Other/Please describe _____
- ○ I see multiple providers

My Primary healthcare provider listens to me
- ○ Always
- ○ Usually
- ○ Sometimes
- ○ Never
- ○ No experience

My primary healthcare provider cares about me
- ○ Always
- ○ Usually
- ○ Sometimes
- ○ Never
- ○ No experience

My primary healthcare provider answers my questions
- ❍   Always
- ❍   Usually
- ❍   Sometimes
- ❍   Never
- ❍   No experience

My primary healthcare provider spends enough time with me
- ❍   Always
- ❍   Usually
- ❍   Sometimes
- ❍   Never
- ❍   No experience

My primary healthcare provider involves me in decisions
- ❍   Always
- ❍   Usually
- ❍   Sometimes
- ❍   Never
- ❍   No experience

My primary healthcare provider respects my choices
- ❍   Always
- ❍   Usually
- ❍   Sometimes
- ❍   Never
- ❍   No experience

My primary healthcare provider deals with my problems
- ❍   Always
- ❍   Usually
- ❍   Sometimes
- ❍   Never
- ❍   No experience

My primary healthcare provider engages me in my care
- ❍   Always
- ❍   Usually
- ❍   Sometimes
- ❍   Never
- ❍   No experience

My primary healthcare provider is helpful to me
- ❍   Always
- ❍   Usually
- ❍   Sometimes
- ❍   Never
- ❍   No experience

My primary healthcare provider respects me
- ❍   Always
- ❍   Usually
- ❍   Sometimes
- ❍   Never
- ❍   No experience

My primary healthcare provider supports my decisions
- ❍ Always
- ❍ Usually
- ❍ Sometimes
- ❍ Never
- ❍ No experience

My primary healthcare provider sees me when I ask
- ❍ Always
- ❍ Usually
- ❍ Sometimes
- ❍ Never
- ❍ No experience

My primary healthcare provider provides me with information
- ❍ Always
- ❍ Usually
- ❍ Sometimes
- ❍ Never
- ❍ No experience

How often was each of the following statements true for you during the past 4 weeks?

I had a hard time doing what the doctor suggested I do
- ❍ None of the time
- ❍ A little of the time
- ❍ Some of the time
- ❍ A good bit of the time
- ❍ Most of the time
- ❍ All of the time

I followed my doctor's suggestions exactly
- ❍ None of the time
- ❍ A little of the time
- ❍ Some of the time
- ❍ A good bit of the time
- ❍ Most of the time
- ❍ All of the time

I was unable to do what was necessary to follow my doctor's treatment plans
- ❍ None of the time
- ❍ A little of the time
- ❍ Some of the time
- ❍ A good bit of the time
- ❍ Most of the time
- ❍ All of the time

I found it easy to do the things my doctor suggested I do
- ❍ None of the time
- ❍ A little of the time
- ❍ Some of the time
- ❍ A good bit of the time
- ❍ Most of the time
- ❍ All of the time

Generally speaking, how often during the past 4 weeks were you able to do what the doctor told you?
- ○ None of the time
- ○ A little of the time
- ○ Some of the time
- ○ A good bit of the time
- ○ Most of the time
- ○ All of the time

Instructions: Please read each group of statements carefully, and then pick out the one statement in each group that best describes the way you have been feeling during the past month.

My health has affected relationships in my family
- ○ Not at all
- ○ Sometimes
- ○ Quite often
- ○ Most of the time

I have felt lonely
- ○ Not at all
- ○ Sometimes
- ○ Quite often
- ○ Most of the time

I have felt good about my appearance
- ○ Not at all
- ○ Sometimes
- ○ Quite often
- ○ Most of the time

I have worried about my health
- ○ Not at all
- ○ Sometimes
- ○ Quite often
- ○ Most of the time

I have worried about other people's attitude towards me
- ○ Not at all
- ○ Sometimes
- ○ Quite often
- ○ Most of the time

I have felt tired
- ○ Not at all
- ○ Sometimes
- ○ Quite often
- ○ Most of the time

I have had as much energy as usual
- ○ Not at all
- ○ Sometimes
- ○ Quite often
- ○ Most of the time

I have felt happy about the future
- ○ Not at all
- ○ Sometimes
- ○ Quite often
- ○ Most of the time

Instructions: Please read each group of statements carefully, and then pick out the one statement in each group that best describes the way you have been feeling during the past month.

Feeding
- ○ Unable
- ○ Needs help cutting, spreading butter, etc., or requires modified diet
- ○ Independent

Bathing
- ○ dependent
- ○ independent (or in shower)

Grooming
- ○ needs help with personal care
- ○ independent face/hair/teeth/shaving (implements provided)

Dressing
- ○ dependent
- ○ needs help but can do about half unaided
- ○ independent (including buttons, zips, laces, etc.)

Bowels
- ○ incontinent (or needs to be given enemas)
- ○ occasional accident
- ○ continent

Bladder
- ○ incontinent, or catheterized and unable to manage alone
- ○ occasional accident
- ○ continent

Toilet use
- ○ dependent
- ○ needs some help, but can do something alone
- ○ independent (on and off, dressing, wiping)

Transfers (bed to chair and back)
- ○ unable, no sitting balance
- ○ major help (one or two people, physical), can sit
- ○ minor help (verbal or physical)
- ○ independent

Mobility (on level surfaces)
- ○ immobile or < 50 yards
- ○ wheelchair independent, including corners, > 50 yards
- ○ walks with help of one person (verbal or physical) > 50 yards
- ○ independent (but may use any aid; for example, stick) > 50 yards

Stairs
- ❍ unable
- ❍ needs help (verbal, physical, carrying aid)
- ❍ independent

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Biographical Information

Brian Holland is an Assistant Professor at Texas A&M University Health Science Center College of Nursing. His area of expertise is in critical care nursing. Holland holds a Bachelor of Science in Nursing from Columbus State University and a Master of Science in Nursing from Lubbock Christian University. He is a member of Sigma Theta Tau International Honor Society for Nurses and is the recipient of the 2013 Ferne C. Newman Kyba Endowed Fellowship from the UT Arlington College of Nursing. His research interests focus on individuals with chronic disease and disabilities. Holland is committed to multiple sclerosis (MS) research having personal ties to individuals with the disease. His research focuses on improving quality of life among individuals with MS and all those with chronic disease. Holland's future research plans include targeting factors that negatively affect quality of life among persons with MS in order to optimize functional ability and self-management. Additionally, Holland plans to explore models of patient-centered care delivery for persons with MS and other chronic diseases. Holland's hope as a Nurse Scientist, is to contribute innovative research that assists those with chronic disease optimize their daily living.