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THE EFFECTS OF MATCHED AND MISMATCHED SOCIAL SUPPORT ON ANXIOUS AND DEPRESSIVE SYMPTOMS IN WOMEN WITH MULTIPLE SCLEROSIS

BY

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Submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy

Department of Professional Psychology and Family Therapy Seton Hall University

2021

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ABSTRACT

There have been many significant findings and contributions to the literature on multiple sclerosis (MS) concerning both physical and mental well-being of individuals who are diagnosed with this illness. While MS is more commonly known now, more than before, there are many obstacles and challenges individuals diagnosed with MS face than people realize. Symptoms that affect individuals with MS are not easily recognized such as fatigue, blurry vision, issues with dexterity, bodily pain, numbness in extremities, and more. Due to the nature of this disease, and many adaptations in life individuals have to make due to their symptoms, studies have shown this population significantly suffers from anxious and depressive symptoms and disorders. A risk factor for these mental health issues is being of the female gender, and as there are more women afflicted with MS than men, they were the primary focus of this study.

Social support has been found in previous studies to have a positive effect on anxious and depressive symptoms, decreasing their presence in individuals with MS. Other studies found, however, that this was not the case. It was important in this study to distinguish perceived social support versus desired social support and that, perhaps, this was a defining feature in mixed results in the literature. The purpose of this study was to determine if a match or mismatch in social support affected anxious or depressive symptoms in women with MS.

Social support groups were created based on the perceived and desired social support of each participant: null support, positive congruent support, support omission, and support commission. These four categories were also distinguished by matched social support (null support, positive congruent support) and mismatched social support (support omission, support commission). An additional important exploration for MS literature was the differences in women with relapsing-remitting (RRMS) and primary progressive (PPMS). This study focused on the anxious and depressive symptoms in the four social support groups as well as the potential differences in women with RRMS versus PPMS.

The results were mixed, with results pointing to anxious symptoms having a significant relationship with social support, while depressive symptoms did not. The analyses, however, found that there was a negative relationship between anxious symptoms and social support, a surprise, but not unheard of in past studies. Due to a low number of participants with PPMS, the data were unable to support hypotheses comparing individuals with RRMS and PPMS.

A significant aspect of this study was the timing of data collection. Data were collected during the COVID-19 pandemic. This is discussed, along with other limitations that promote future studies, exploring the relationship between social support and anxious and depressive symptoms.

Keywords: multiple sclerosis, social support, anxiety, depression

Dedication

I would like to dedicate this work to my family. Thank you to you all for the love you have given me throughout my life and this journey.

Thank you most importantly to,

My grandparents, George and Helen Kaplaneris and Dimitrios and Heleni Thomopoulos, whose love I feel every day and who would be so happy for me, and smiling from ear to ear.

My parents, John and Effie Thomopoulos, for their unconditional love and support. They are my biggest cheerleaders and have never doubted that I was capable of this achievement. Thank you for giving me the world, and for being mine. I love you.

Lastly, to my partner in life, Billy, thank you for loving me without conditions. Thank you for helping me always so that I may help my patients now and in the future. I love you.

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I would like to acknowledge and thank my committee for their time, patience, and support throughout this journey. A special thank you to my advisor, Dr. Pamela Foley. Thank you for your efforts, support, responses to all my emails, edits to all I write, guidance in all my statistics, and dedication to me, and all your students.

I would also like to recognize and extend a thank you to two of my past supervisors and mentors, who helped me navigate and work with this population, Dr. Elizabeth Kera and Dr. Brian Amorello. It was truly an honor to work with, learn from, and be guided by you both. Thank you for the investment you made in me as a student, clinician, and individual.

Thank you to the wonderful women who inspired this dissertation, you are all resilient, worthy warriors.

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Chapter I

Introduction

Individuals diagnosed with multiple sclerosis (MS), throughout the development of their disease, must deal with and work though many psychosocial obstacles. They must overcome alterations to their employment status, cognitive skills, relationship changes, and their abilities to do daily tasks and activities (Morrow et al., 2010; Simmons, 2010; Sutton, 2017). These struggles and obstacles call for patients to adapt to their new life with MS. These life alterations often take a psychological toll, resulting in anxious and depressive disorders and/or symptoms.

Even for those who are not facing illnesses, anxiety and depressive disorders are common. According to the National Institute of Mental Health (2017a), about 19.1% of adults in the United States have an anxiety disorder, with a higher prevalence in women. Considering the lifespan, about 31.1% of adults in the United States have experienced an anxiety disorder at some point in their lifetime (National Institute of Mental Health, 2017a). The National Institute of Mental Health (2017b) estimated about 7.1% of the adult population had at least one major depressive episode in their lifetime. According to the American Psychiatric Association (2016a), however, individuals with physical health conditions are more likely to have an anxiety disorder. Medical diseases have also been highly associated with depressive disorders (American Psychiatric Association, 2016b).

For individuals diagnosed with MS, the prevalence of depression and anxiety is significantly higher. A systematic review of MS literature revealed a prevalence of significant depressive symptoms of 35% in this population (Boeschoten et al., 2017). The prevalence of anxiety disorders in individuals with MS ranges from 22.1% to 43% (Boeschoten et al., 2017). Additional studies have found significant symptoms of anxiety in the MS population, with a

prevalence rate of 34.2% (Franco, 2014). The literature on MS focuses on anxiety and depression in this population due to the clinical implications of these disorders, including lack of treatment adherence, poor quality of life, and concurrent increase in physical illness symptoms (Butler et al., 2016).

Risk factors and predictors of anxiety in MS have been found to include comorbid depression, being of the female gender, employment, level of disability, higher level of fatigue, and limited social support (Beiske et al., 2008; Garfield & Linclon, 2012; Hartoonian et al., 2015 Jones et al., 2012; Korostil & Feinsten, 2007; Tan-Kristanto & Kiropoulos, 2015; Wood et al., 2013). With these in mind, it is important for the literature to explore more thoroughly anxiety and depression and the impact of such predictors on individuals with MS. This study focused on social support specifically to address and clarify past studies' limitations and conclusions. The remainder of this chapter will introduce the study and the population, definitions of the variables to be explored, hypotheses, and possible limitations of the study.

Statement of the Problem

Individuals with MS live their lives with significant uncertainty, but what they can ensure or be certain of is the unpredictability of their disease. Due to the nature of MS, the symptoms and progression for each individual present in a variety of ways. Due to the covert nature of symptoms, many people look at someone with MS and have no idea that he or she has been afflicted with this disease. When a person sees an individual with MS who is in a wheelchair, he or she may know to help by opening the door or fetching something for them that is not easily accessible, but it may not be as clear how to help those whose symptoms that are not visible to the eye. Some of these symptoms, such as fatigue and cognitive impairment, cannot be seen and are less understood by others. Many of these symptoms, as well as the added layer of unpredictability, can lead to stress and take a toll on individuals with MS (Kirchner & Lara, 2011). This stress promotes more psychological symptoms, the two most common being depressive and anxious symptoms, and can often exacerbate the symptoms of MS itself (Beiske et al., 2008; Kirchner & Lara, 2011; Marrie et al., 2015; Patten et al., 2017). Patients often report that anxiety or depression often cause their MS to feel worse during that period. Although researchers have found that social support promotes better mental health in individuals with MS, (Henry et al., 2019; Kirchner & Lara, 2011), the fact that many people are not fully aware of the symptoms or level of support individuals with MS need, the support offered to these individuals may be limited.

Significance of the Study

While studies show the positive effects that social support can provide for mental health, not all social interactions, even well-meaning, are perceived as positive. However, many existing studies neglect the potential negative aspect to social interactions. It is important to consider the negative effects of social support, especially in those who are chronically ill. Previous studies have found that support that was perceived as negative was strongly related to negative mental health outcomes (Helgeson et al., 2000; Manne et al., 1997; Mohr et al., 2001; Rook, 1984; Uccelli et al., 2004; Wakefield et al., 2013). For this reason, it is important to explore the possible mismatch between the levels of social support individuals with MS desire and what they receive, and how this may be impacting their mental health, specifically anxious and depressive symptoms. Previous authors have reported nonsignificant findings related to social support and mental health, which may be explained by the mismatch of social support (Tough et al., 2017). Additionally, as the mismatch of social support has been studied in other chronically ill populations, this study could help fill in the gap in the literature. This exploration could also

explain the conflicted or lack of findings in the literature and provide guidance for healthcare providers, caregivers, and loved ones of individuals with MS.

The Nature of Multiple Sclerosis

Multiple sclerosis (MS) is an often unpredictable and chronic disease of the central nervous system (Sutton, 2017). This neurological condition is caused by damage to myelin, the part of the nervous system responsible for the rapid transmission of information from one nerve cell body to another. MS is diagnosed in more than 2.1 to 2.3 million people worldwide with a variety of symptoms including fatigue, visual problems, movement and coordination issues, bladder dysfunction, sexual dysfunction, cognitive changes, and more (Sutton, 2017). MS comes with a lot of uncertainty, and while many illnesses have the same presentation in majority of individuals, MS presents in a variety of ways. Individuals may have symptoms with physical consequences that people can see and observe, but there are others that are invisible, such as fatigue, altered sensation, weakness, struggles with focus and concentration, and others. Due to the invisibility of these symptoms, it can be difficult for many patients to communicate and describe the obstacles they are facing and the effects on their lives to those around them.

Epidemiological studies indicate that MS is mostly found in Western countries, particularly those with temperate climates. Although individuals worldwide can have MS, it is clear that it most commonly occurs far from the equator. In addition to this, women are three times more likely to be diagnosed with MS than are men (Birnbaum, 2013; Sutton, 2017). The prevalence of MS in women has increased and the age of diagnosis has become younger, according to multiple sources (Debouverie et al., 2007; Grimaldi et al., 2006; Sutton, 2017). Studies have found an increase in prevalence and incidence rate in many countries, one in particular found "a 2.4-fold increase in prevalence and about 2-fold increase in incidence across two decades," from January of 1993 to December of 2002 (Grimaldi et al., 2006, p. 29). Some of the literature explores possible reasonings behind the increase, which include better access to resources and knowledge to help with diagnosis. The literature also considers other aspects like genetic and environmental factors (Debouverie et al., 2007; Sutton, 2007). MS can present in children, but it is reported to occur more commonly between the ages of 15 and 45. Diagnosis often occurs between the late 20s and mid-30s, but MS can also initially present as late as 60 years old (Birnbaum, 2013; Miclea et al., 2019; Sutton, 2017).

There are four subtypes of MS, two of which are more common. In the MS population, 85% of individuals have relapsing-remitting (RRMS), 15% have primary-progressive (PPMS), and 5% have progressive-relapsing (PRMS). The fourth, subtype secondary-progressive MS (SPMS), occurs in individuals who have RRMS and eventually transition to SPMS 10 to 20 years after their diagnosis. Relapsing-remitting MS is the subtype that afflicts most of the MS population and its name describes its presentation well. This type of MS usually presents when an individual is in their 20s or 30s, a younger age, in comparison to the other subtypes. An individual with RRMS may have periods of partial remission, alternating with periods of relapse, in which a new symptom of MS will present itself or an old symptom will return. These symptoms can last for days, weeks, or months, and vary in degree, making it difficult for many people to resume their normal routines. Early on in RRMS, individuals' symptoms are able to resolve completely. However, if an old symptom, for example, tingling in a leg reemerges and lasts a week, there is a possibility that this symptom may not completely resolve; this is a sign of disease progression. With progression of MS, each individual's baseline will change, and some symptoms may not completely resolve (Birnbaum, 2013).

Primary-progressive MS is the next most common. It differs from RRMS in that there is no time period during which symptoms are present and then resolve; rather, in PPMS, symptoms begin to appear in a more gradual fashion and become more apparent and severe with time, with no break of symptoms. An unpredictable aspect, specific to PPMS, is that some individuals with this form can become physically disabled after a year, while others may take a decade or more. Also differing from RRMS, PPMS is often diagnosed later in life, when individuals are in their 40s and 50s, while RRMS is most diagnosed when an individual is in their 20s and 30s. Another difference is that PPMS afflicts men and women equally, while RRMS is more common in women (Birnbaum, 2013). Progressive-relapsing MS is similar to both PPMS and RRMS. Its characteristics include the progressive worsening of symptoms like in PPMS; however, it is also characterized by relapses with more severe symptom presentation like in RRMS.

Secondary-progressive MS is the evolution of RRMS for about half of the individuals who have RRMS. The pattern of the MS changes with fewer relapses, but instead a gradual progression of symptoms emerges like in PPMS. Once the relapses stop and the progression is continuous, that is when an individual goes from RRMS to SPMS (Birnbaum, 2013). According to the National MS Society (2018), prior to the major new treatments, 50% of individuals diagnosed with RRMS would have SPMS after 10 years, and within 25 years, 90% of those individuals would transition to having SPMS. Today, however, it is unclear how new therapies will alter these statistics and delay the course of SPMS for those with RRMS (Miclea et al., 2019; National MS Society, 2018; Sutton, 2017; U.S. Department of Veteran Affairs, 2018).

Social Support

Social support is an important aspect of any social relationship where the giver intends to be helpful by aiding and assisting the recipient to his or her benefit (Barrera et al., 1981; Cohen, 2004; Glanz et al., 2008). Barrera and Ainlay (1983) and Glanz et al. (2008) defined four types of social support: emotional, instrumental/tangible, informational/guidance, and appraisal/feedback (Barrera & Ainlay, 1983; Glanz et al., 2008; Stokes & Wilson, 1984). Emotional support is often in the form of expressions of empathy, love, care, and understanding (Barrera & Ainlay, 1983; Cohen, 2004; Glanz et al., 2008). Instrumental/tangible support is aid and service, such as walking a dog for an immobile person (Barrera & Ainlay, 1983; Cohen, 2004; Glanz et al., 2008). Informational/guidance support comes in the form of advice and information (Barrera & Ainlay, 1983; Cohen, 2004; Glanz et al., 2008). Appraisal/feedback is providing information that can be useful for an individual's self-evaluation of their behavior or thoughts (Barrera & Ainlay, 1983; Glanz et al., 2008). These different forms can also be supplied by family members, friends, neighbors, and others (Barrera et al., 1981). When articles refer to social support, they are often referring to the received or perceived social support that the recipient is being given. Therefore, *perceived social support* is the social support the recipients believe they are getting. However, most instruments measuring social support are working under the assumption that the recipient wants the support he or she is being given and that there is a positive feeling surrounding receiving this social support (Ganz, 2002; Helgeson et al., 2000; Matire et al., 2002). While social support is intended to be helpful, it may not be wanted by the recipient and therefore he or she may view this "support" in a negative light. For that reason, the present study will also measure *desired social support*. Desired social support is support that is wanted by the recipient. The combination of looking at perceived and desired social support will help to determine if there is a match or mismatch of social support for the participants.

Social support has been linked to health benefits that positively affect well-being and quality of life (Henry et al., 2019; Sutton, 2017). Studies have shown that a lack of social support

can lead to ill effects on health as well as negative psychological impact (Baumeister & Leary, 1995; Sutton, 2017). It is important to explore this construct, separating perceived and desired social support, as social support overall is an important factor in chronically ill populations (Cohen, 2004; Cohen & Wills, 1985; House et al., 1988).

Anxiety

The *Encyclopedia of Psychology* described anxiety as an emotion characterized by feelings of tension, worried thoughts, and physical changes (Kazdin, 2000). Among the somatic symptoms of anxiety are numbness or tingling, wobbliness in legs, and feeling shaky/unsteady (Beck Anxiety Inventory, Beck et al., 1988), all of which overlap with MS symptoms. Therefore, while anxiety can have physical symptoms, to prevent misrepresentation of physical symptoms of MS as somatic symptoms of anxiety, the present study focused only on non-somatic anxious symptoms.

As previously mentioned, anxiety is highly prevalent in the MS population (Boeschoten et al., 2017; Butler et al., 2016; Henry et al., 2019; Korostil & Feinstein, 2007; Wood et al., 2013). The variability and lack of control over MS and its effects on an individual's life is a common source of anxiety. Anxiety comorbid with MS has been significantly linked to poor psychosocial functioning, increased pain, poor quality of life, and worsening in negative health behaviors such as smoking and substance use (Sutton, 2017). Anxiety has also been found to be associated with disability and the fear of developing more disabling handicaps as the disease progresses (Benedict et al., 2008; Stenager et al., 1994). Gay and colleagues (2010) found that in individuals with MS, trait anxiety directly increased depressive symptoms, and that anxiety contributed to the feeling of low satisfaction with one's social support. In further exploration,

Gay and others (2017) confirmed anxiety as a direct and indirect factor for depression in individuals with MS, making these two constructs important to examine together.

Depression

Depressive symptoms can include feeling sad, loss of interest, difficulty sleeping, fatigue, loss of sleep, and worthlessness (American Psychiatric Association, 2013). Particularly in individuals with MS, fatigue and pain has been found to be associated with depression (Benedict et al., 2008). Structural changes in the brain such as lesions have also been linked to the relationship between MS and depression (Lotrich et al., 2011; Sutton, 2017). In terms of the different subtypes of MS, major depressive disorder has been found to be more prevalent in patients with PPMS than RRMS (Lorefice et al., 2015).

Gay and colleagues (2010) found that satisfaction with social support predicted lower levels of depression in individuals with MS. De la Vega et al. (2018) found that in individuals with MS, spinal cord injury, and muscular dystrophy reported a decrease in depressive symptoms when they had an increase in social support. There have been conflicting results, however, as Tough et al. (2017) systemically reviewed published studies looking at the associations between social relationships and mental health. Through their search and analyses, they found many studies reported a significant association between social support and depression but noted that there were inconsistencies. They explained these inconsistences through unwanted social support, which may have resulted in negative consequences (Tough et al., 2017). The authors further noted the limitation of mismeasuring of social support in terms of perceived versus received, a correction to be made in this study.

Definition of Terms

Perceived social support: Perceived social support is an individual's assessment of the availability of the social support he or she is given (Roohafza et al., 2014). In this study, perceived social support was defined as the social support the recipient believes he or she is getting from a support person. For the purposes of this study, perceived social support was measured through a yes or no response to the question, "Does your support person do this?" to each statement on the Inventory of Socially Supportive Behaviors (ISSB) (Barrera et al., 1981; Barrera & Baca, 1990; Barrera et al., 1981).

Desired social support: Desired social support is defined the social support needed by an individual (Linden & Vodermaier, 2012). In this study, desired social support was defined as the social support the recipient wants from his or her support person. For the purposes of this study, desired social support was measured through a yes or no response to the question, "Do you want your support person to do this?" to each statement on the ISSB (Reynolds & Perrin, 2004).

Positive congruent support: Positive congruent support is defined as a positive support where social support is wanted and received (Reynolds & Perrin, 2004). For the purposes of this study, positive congruent support was defined as the individual's report that she or he both wanted a certain support and received that support.

Support omission: Support omission is defined as social support is wanted but is not received (Reynolds & Perrin, 2004). In this study, support omission was defined as the individual's report that she or he wanted a certain support but did not receive that support.

Support commission: Support commission is defined as social support is not wanted, but it is received (Reynolds & Perrin, 2004). In this study, support commission was defined as the individual's report that she or he did not want a certain support but received that support.

Null support: Null support is defined as social support is not wanted, and it is not received (Reynolds & Perrin, 2004). For the purposes of this study, null support was defined as the individual's report that she or he did not want a certain type of support and did not receive that support.

Mismatched social support: Mismatched social support is defined as the misalignment of social support wanted and social support received (Reynolds & Perrin, 2004). For the purposes of this study, mismatched social support is defined as the participant desiring a certain level of social support and not receiving that level of social support. Mismatched social support, in this study, is any support that is not positive congruent support or null support.

Matched social support: Matched social support is defined as a match between the social support the individual wants and the social support the individual receives (Reynolds & Perrin, 2004). For the purposes of this study, matched social support was defined as the participant desiring a certain level of social support and receiving that level of social support.

Anxiety: This study defined anxiety as having non-somatic anxious symptoms as measured by the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).

Depression: For the purposes of this study, depression was defined as having any nonsomatic depressive symptoms as measured by the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).

Research Questions

The present study addressed the following questions:

1. How does degree of match in social support (i.e., support omission or support commission) affect anxious symptoms?

2. How does degree of match in social support (i.e., support omission or support commission) affect depressive symptoms?

3. Does the subtype of MS affect the level of depressive symptoms?

4. Does the subtype of MS affect the level of anxious symptoms?

Hypotheses

The hypotheses that were tested in this study are as follows:

1a. Participants who report support omission will report higher levels of anxious symptoms than those with positive congruent or null support.

1b. Participants who report support commission will report higher levels of anxious symptoms than those with positive congruent or null support.

2a. Participants who report support omission will report higher levels of depressive symptoms than those with positive congruent or null support.

2b. Participants who report support commission will report higher levels of depressive symptoms than those with positive congruent or null support.

3a. Participants who have PPMS will report higher levels of depressive symptoms than participants with RRMS.

4a. Participants who have PPMS will report higher levels of anxious symptoms than participants with RRMS.

Limitations

As with all studies, there are limitations to the sample and methodology. First, the participants were recruited online and self-selected. Additionally, as this is anonymous, there is no way to verify if the participants are truly within the inclusion criteria for this study. The participants were self-reporting that they are formally diagnosed by a neurologist with MS, and it

was also up to them to answer truthfully on their demographic questions. With this in mind, it is possible that the results would not truly represent the entire population of women with MS, and therefore the results would not be generalizable.

The measures used for this study are all self-report, which poses an additional limitation. Participants were asked about their anxious and depressive symptoms and may over- or underestimate their symptoms. As mental health can be stigmatized, some participants many not want to admit they are experiencing symptoms and not answer the questions accurately. When considering the social support scale being used, it asks about specific examples of social support, some of which individuals may not receive or desire, and therefore their responses may not be an accurate reflection of their social support situations.

An added limitation is that sample for this study only includes women. While the intent of this study is to study women with MS, these results cannot be generalizable to the entire MS population, as men will be absent from the sample collected. Participants also must be computer or technology literate in order to complete this survey. The survey can be accessed only on the Internet, and participants must be able to access it on a device such as a computer, smartphone, or tablet. Some individuals are unable to use these devices or have access to this type of technology or Internet. Others who may not be able to easily access the survey are individuals with MS whose symptoms have progressed. For example, if an individual is attempting to use their fine motor skills but are unable to due to symptom progression, they may not be able to complete the survey successfully. It is possible that these individuals could ask for help to complete the survey from a support person; however, their responses may then not be truthful, therefore not being an accurate reflection.

Chapter II

Review of the Literature

This chapter will provide reviews and discussion of past literature relevant to this study. The chapter will include the following sections: (a) overview of anxiety and depression in multiple sclerosis (MS), (b) predictors of anxiety and depression in MS, (c) impacts of anxiety and depression in MS, and (d) social support. The sections will provide information and critiques about past studies and literature that has been published related to each.

Overview of Anxiety and Depression in Multiple Sclerosis

Multiple sclerosis (MS) is a lifelong progressive disease that results in unpredictable symptoms and can create a range of disabilities that can lead to reduction in activity in all areas of life. These disabilities can be physical, emotional, and cognitive in nature. The variety of symptoms stems from the possibility for lesions to form anywhere in the central nervous system (Béthoux et al., 2013; Sutton, 2017). The unique locations of lesions on each individual account for the variable presentation in each person with MS. Most of these individuals, however, have similar struggles with the treatment processes and drug side effects that present great challenges for individuals coping not only with the disease but with their everyday lives. The lack of control and full understanding of MS often takes a toll and, at times, makes it difficult to differentiate between psychiatric symptoms and the physical effects of MS. For example, somatic symptoms of depression, including fatigue, are comparable to some MS symptoms. However, fatigue worsens throughout the day in individuals with MS, while in depression fatigue improves or energy levels change throughout the day (Béthoux et al., 2013). It is important to discuss mental health, as individuals with MS have been found to have two times the risk of suicide than the general population (Béthoux et al., 2013; Feinstein & Pavisian, 2017). However, it is also

significant that many of those with MS who reported feeling suicidal previously had diagnoses of depression, anxiety, comorbid depression–anxiety disorders, and alcohol abuse disorder (Feinstein, 2002). Severe depression, alcohol abuse, and living alone reportedly had "an 85% predictive accuracy for suicidal intent" (Feinstein, 2002, p. 674).

There are many medical conditions and diseases that are associated with psychological struggles as well, one in particular being cancer. In a study by Linden and colleagues (2012), they utilized a large sample of patients with all different types of cancers and was the first of its time to provide data on anxious and depressive symptoms for this diverse cancer population. They found that the data implied that within the cancer population there are distinct risk groups when it came to cancer type, gender, and age. There is a substantial amount of literature addressing psychological constructs related to those diagnosed with a medical condition or disease, two of which are cancer and MS. Similar to past cancer research lacking comparisons between different types of cancer, there is limited literature on the differences between the MS subtypes, as previously mentioned. This limitation is significant, as the different subtypes of MS can have different clinical implication as patients may be exhibiting different needs and distress (Henry et al., 2019). For example, an individual diagnosed with PPMS may have more physical limitations than an individual with RRMS, resulting in different needs and a different type of psychological toll. Those with PPMS present symptoms in a continuous manner with no break in symptoms like in RRMS, which at times results in physical disability within a year, making these individuals' needs more apparent, such as a wheelchair, walker, or physical assistance from another individual (Birnbaum, 2013). Additionally, when considering treatment options, usually patients with RRMS have more options than those with PPMS, which for some people could be a great source of strain and distress leading to depressive symptoms (Béthoux et al., 2013).

Unfortunately, Henry and colleagues (2019) noted, many studies have difficulty finding enough participants that vary in MS subtypes to examine their significant differences. Lorefice and colleagues (2015) sought to compare mood disorders between individuals with PPMS and RRMS. They found a higher prevalence of major depressive disorder in individuals with PPMS than in those with RRMS. It was thought that due to the progressive nature of PPMS that individuals would have difficulty with adjustment. This can be explained through past studies that associated higher levels of disability with depressive symptoms, as individuals with PPMS tend to have more physical disabilities than those with RRMS (Stapleton et al., 2017).

Kirchner and Lara (2011) explored the loss of physical functioning as a mediator between social functioning and stress and depressive symptoms. In a study conducted in Spain, with a sample of 65 individuals with MS, 71% women and 29% men, they defined social functioning as visiting and interacting with family and friends. They found that loss of social functioning was a mediator between MS stress and depression symptoms, while loss of physical functioning, as an additional mediator, was not as strongly associated with depressive symptoms. They proposed the reasoning behind not finding a significant association between loss of physical functioning and depressive symptoms was due to social functioning. The thought was that those with strong social functioning, even with physical limitations, may not have had depressive symptoms. Kirchner and Lara did acknowledge in their demographics table that 81.5% of participants had RRMS, while only 18.5% had PPMS, but was not included in their analysis. It would have been helpful to analyze the data by subtype, as those with PPMS have more loss of physical functioning than those with RRMS. PPMS follows a continuous progression, with most cases causing spinal cord dysfunction (Birnbaum, 2013). This subtype of MS is "a more severe deterioration than relapsing-remitting form" (Sutton, 2017, p. 23). Many symptoms attributed to

PPMS are those related to loss of physical functioning such as problems with walking, weak legs, and balance issues that lead to the use of a cane or other walking aids. An important aspect of PPMS as noted is its deleterious effects including on memory. Individuals with PPMS generally have worse results on memory loss than other individuals with MS (Sutton, 2017). Additional effects of the subtypes, such as the damaging ones of PPMS, should be taken into consideration when making statements regarding depression in individuals with MS.

An important variable noted in the literature is that of gender, as women not only are three times more likely to be diagnosed with MS, but they are also more likely to suffer from anxiety disorders in both the general and MS populations (Harbo et al., 2013; Miclea et al., 2019; Sutton, 2017). According to studies, psychological factors have been found to be better predictors of adjustment to MS than magnitude of neurological disability, symptom severity, and other illness-related factors (Chwastiak et al., 2002; Dennison et al., 2009). The prevalence rates of major depressive disorder and anxiety disorders in the MS population are 54% and 35.7% (Béthoux et al., 2013). The literature has a multitude of findings related to the relationship between mental health and other risk and predictive factors in the MS populations. The gaps that are present in the MS literature are being able to examine the difference between the subtypes of MS as well as focusing in on gender.

Impacts of Anxiety and Depression in Multiple Sclerosis

Individuals with MS have a higher prevalence of depression and anxiety (Boeschoten et al., 2017). In the general population, within the United States, approximately 19% of adults have been diagnosed with an anxiety disorder, and about 31% have been diagnosed with an anxiety disorder at some point in their life. About 7.1% of adults in the United States have been diagnosed with at least one depressive episode in their life (National Institute of Mental Health,

2017). Stein and his colleagues (2005) sought to examine the impact of anxiety disorders and major depression and its impacts on health-related quality of life. They studied 480 primary care outpatients who had been diagnosed with an anxiety disorder with or without major depression. With all the data collected they completed multivariate regression analyses and found "no doubt that anxiety disorders carry with them a profound burden of disability for patients in the primary care setting" (p. 1168). An important finding when considering the chronically ill population was that the effects of anxiety disorders were just as significant. The authors concluded that anxiety disorders are just as debilitating as major depression and should be taken into consideration as predictors of poor functioning and reduced health-related quality of life.

Mental health has been an important factor in many chronically ill populations. Oliveira and colleagues (2019) were concerned with the mental health of patients suffering from chronic low back pain and assessed how the use of a multidisciplinary approach provided patients would impact depressive and anxious symptoms and clinical outcomes. Utilizing the Hospital Anxiety and Depression Scale (HADS) as well as a pain inventory, the data showed that anxiety, depression, and their interactions were associated with changes in the pain and disability after 1 year. From this longitudinal study, they concluded that that it is vital to prescreen for anxiety and depression separate from the patients' medical condition so as to attend to each issue properly and effectively. These were similar findings to Pompe and team (2018), who hypothesized that depression and anxiety would be associated with poor surgical outcomes and greater complications in patients who underwent a radical prostatectomy. To measure these outcomes, the patients filled out the Patient Health Questionnaire – 4 (PHQ-4), which were analyzed along with surgical outcomes such as length of stay in the hospital, blood loss, and complications. They also looked at functional outcomes and oncological outcomes. In the end, they concluded that

those with higher depression and anxiety scores were at higher risk for complications after surgery and worse functional outcomes such as urinary incontinence. The recommendations of these two studies are that it is important to understand patients' anxiety and depression as they are often associated with worse medical outcomes.

While there are many studies that have addressed the impacts of anxiety and depression on various medical conditions and illnesses, it is important to be able to examine each condition or illness individually, as the impact may vary by condition. Korostil and Feinstein (2007) assessed prevalence rates and clinical correlates of anxiety disorders in patients with MS, and they found that lifetime prevalence of any anxiety disorder was 35.7%. Additionally, they found that most of their subjects had not been properly diagnosed and therefore had not received treatment. These findings suggest that anxiety disorders are overlooked in MS patients. The study further found that significant risk factors include female gender, comorbid depression, and limited social support.

Feinstein et al. (1999) assessed the effects of anxiety on 152 individuals with MS. Using the HADS along with The General Health Questionnaire and scale assessing suicidal thoughts or intent, they found that women with MS were more likely to have anxiety than males with MS. Further, when participants presented with both anxiety and depression, this was connected with increased thoughts of self-harm, somatic complaints, and great social dysfunction. The authors noted that as the somatic symptoms of anxiety often mimic those of MS, in many instances anxiety is overlooked. It is important to increase awareness of anxiety in this population, as the comorbid findings suggest stronger negative effects on physical and social factors, especially in women. Fiest and colleagues (2016) reviewed studies that evaluated the effectiveness of psychological and pharmacological treatments for depression and/or anxiety in individuals with MS. They found that pharmacological and psychological treatments for depression were effective in reducing depressive symptoms for individuals with MS. However, they stated that evidence from existing studies was insufficient to assess the effectiveness of treatment for anxiety on individuals with MS.

Kratz and colleagues (2017) examined the daily changes in pain, fatigue, depressed mood, and cognitive function in 102 adults with MS. Of the participants, 79 were women, and 84 identified as White. The mean age of the participants was 44.85 with a range of 23 years old to 67 years old. There were four outcome variables, positive affect and well-being, ability to participate in social roles and activities, upper extremity functioning, and lower extremity functioning. In terms of measuring all of the variables listed, the authors noted that they were unable to fully examine the range of outcomes. Their results showed an increased daily depressed mood was negatively related to positive affect and well-being, and pain played a prominent role in social functioning. The PPMS subtype was related to lower abilities to participate in social roles and activities, as was depressed mood. While they were able to look at the different subtypes in MS, PPMS only made up 10.8% (n = 11) of their participants. It is important to further these explorations with more detail and full range in relation to depression, and more specifically the differences between individuals in different MS subtypes and the differing impacts depression may have on them.

Stern et al. (2018) reported mixed findings in regard to the association between age and depression in individuals with MS. The participants consisted of 42 women and 15 men, the majority, 52.6%, of whom identified as African American, 40.4% identified as Caucasian, and

7.0% identified as Hispanic. The participants were divided into three age groups: 35–44, 45–54, and 55–65 years of age, with an average age of 50. The goal for this team was to examine the three age groups, all of which had been diagnosed with MS, and to measure their depressive symptoms as well as their quality of life. They found that older participants with MS reported lower levels of depression and higher quality of life than those in younger groups. While they provided some excellent explanations and support for their findings, the limitations were notable. The age range of participants was broad (35–65), with the total number of participants fairly small (N = 57), and this was then broken up into three smaller groups. The small sample size and three compared groups limited their ability to utilize more elaborate analyses. Additionally, as more individuals are being diagnosed younger (early 20s), this sample is not representative of a large portion of the MS population (Debouverie et al., 2007; Grimaldi et al., 2006; Sutton, 2017). The results for this study were consistent with findings for the general population; however, if these results are not accurate and generalizable this could impact future recommendations for patients by their physicians. It is important to recognize the potential predictors and risk factors for individuals with MS so that their mental health and well-being can be appropriately monitored by their healthcare providers. Psychiatric disorders such as depression and anxietyrelated illnesses can be overlooked in individuals with MS, yet they can have a negative and significant impact on their quality of life and well-being. With this in mind, it is important to prevent even more suffering for these individuals by attending to their mental health and identifying protective factors that can help them improve (Béthoux et al., 2013)

Predictors of Anxiety and Depression in Multiple Sclerosis

Studies have searched for the etiology of depression, in the MS population, Béthoux et al. (2013) listed a multitude of factors that are specific to MS and contribute, including: brain lesion

location, autoimmune dysregulation, endocrine abnormalities, MS somatic symptoms, cognitive impairment, unpredictability of disease progression, psychosocial stressors, effects on social life, effects on occupation, effects on family, poor coping skills, limited social support, and history of mood disorders. While brain lesions have been linked to depression, no association between anxiety or symptoms of anxiety and MRI abnormalities have been found (Zorzon et al., 2001). Studies have also found predictors of anxiety in the MS population, including the female gender and limited social support (Feinstein et al., 1999; Korostil & Feinstein, 2007).

In 2010, Gay and colleagues investigated the relationship between depression and other factors that may be connected in the MS population, including depression, anxiety, and social support. Of their 115 participants, 36 were men and 79 were women, and 88.2% identified as Caucasian. The age range of these participants was from 27 to 80 years old, with the mean age of 47.22. After collecting data, it was found that 25.9% of the participants presented with depressive symptoms. Of that percentage, 20.5% were moderate and 5.4% were severe. A larger number of patients experienced anxiety: 43.8% of the participants had moderate trait anxiety, 13.4% had high trait anxiety, and 7.1% had very high trait anxiety. Regarding social support, on average, participants reported they had 15 people that supported them, which the authors indicated was lower than general population. The satisfaction with their social support, however, was on average good. Using a path analysis, the authors reviewed the direct and indirect effects of trait anxiety on depression. They found that trait anxiety directly affects depressive symptoms and accounts for over a quarter of the variance. Anxiety also indirectly contributed via two other factors, one being satisfaction with social support and the other being alexithymia, which is defined as "difficulty identifying feelings and distinguishing between feelings and the bodily sensations of emotional arousal; difficulty describing feelings to others; a restricted imagination,

as evidenced by a paucity of fantasies; and a cognitive style that is literal, utilitarian, and externally oriented" (Gay et al., 2010, p. 162). Overall, 40% of the variance in depression was attributed to anxiety. Gay and team (2010) concluded that high trait anxiety, dissatisfaction with social support, and functional disability predict depression in individuals with MS. They stated that these conditions should be given priority for treatment when working with the MS population over other factors. This is an important statement, as many providers attempt to tackle other factors during treatment that may not be as effective as focusing on anxiety and social support. For example, addressing an individual's anxiety through psychotherapy may also improve exacerbations of physical symptoms (Schapiro, 2014; Sutton, 2017). The authors called for additional studies on depression and anxiety in individuals with MS. With all the information obtained by this study, it is important to focus on what is missing from the literature. In discussing their findings, Gay and colleagues (2010) emphasized that their participants had a higher rate of depressive and anxious symptoms than expected, yet they were overall satisfied with their social support. However, their results may not generalize to individuals who were not happy with their social support. A missing piece that also has been discussed in the literature is the differences between PPMS and RRMS. It is possible that the path analysis created would look different if separated by subtype. There is more that needs to be explored in terms of social support and the relationship between anxiety and depression, while incorporating MS subtypes.

Hartoonian and colleagues (2015) measured anxious symptoms of 513 individuals with MS at two points in time, 4 months apart. The total sample included 417 women and 93 men. A majority of participants, 91.8%, identified as non-Hispanic White, while 8.2% were identified as "other." The mean age of these individuals was 51.4 years old. In looking at the subtypes, 55.7% reported having RRMS, 20.2% reported having SPMS, 12.5% had PPMS, and 2% reported not

knowing their particular type of MS. It was found that the participants' current non-somatic symptoms of depression and employment status were risk factors for higher anxiety symptom severity at a 4-month follow-up. With similar interests in anxiety, Gay and team (2017) wished to analyze how anxiety affects coping, emotional processing, emotional balance, and depression in individuals with MS. Using complete data from 189 participants, 121 women and 68 men, with a mean age of 47.2 years, they discovered that anxiety was a strong predictor of depression via both direct and indirect pathways. They concluded through their model that anxiety affects depression through unregulated and negative emotions. With this in mind, they call for early interventions focusing on individual and social factors. Their recommendation for future research includes a consideration for disease specific and psychosocial factors and their involvement in depression.

Emotional distress has been recognized by some as the sixth vital sign in medical care. When patients are suffering emotionally, they are more likely to use health services and visit emergency rooms, which calls for more time and attention to continuously neglected psychological symptoms (Stein et al., 2005). Thus, taking care of these needs involves not only reducing the problems for patients, but also lessening this burden for the healthcare system. As many of the reviews and studies pointed out, anxiety is often overlooked in the MS population, perhaps it is due to the similarities in medical and psychological symptoms, or due to neglect, but regardless of why, it needs to be addressed and corrected.

Social Support

When individuals experience social support, they are often receiving messages of being valued, cared for, loved, and respected by a number of individuals in their lives (Roohafza et al., 2014). Social support has most often been measured in the form of perceived social support, or

the assessment of the availability of social support that is given (Roohafza et al., 2014). Social support has been known to be associated with a variety of issues including self-esteem, anxiety, depression, and general mental health and well-being. Roohafza and colleagues aimed to examine perceived social support and coping styles and their associations with depression and anxiety. Within their non-clinical sample of over 4,500 individuals, 56.1% of which were female and 55.8% were male, the team found that a significant predictor of both depression and anxiety was being female. While they did not report the races or ethnicities of participants, the average age was 36.51 years old. Through a multiple logistic regression analysis, they also concluded that perceived social support from family and others was significant protective factor. When looking at depression, they found that all social supports, family, friends, and others, were found to be protective factors. The authors attributed these findings to the stress-buffering model (Cohen and Wills, 1985).

Cohen and Wills (1985) compared two models of social support to determine which more accurately describes the relationship between stress, social support, and well-being. They examined the main effect model, which is said to be "an overall beneficial effect of support" (p. 347) and the buffering model, which is "a process of support protecting persons from potentially pathogenic effects of stressful events" (p. 347). They defined stress as something that occurs when an individual sees a situation as threatening or demanding and lacks the appropriate resources or coping mechanism to help them through the situation. While they found evidence and support for both models, viewing support as a stress buffer posits that social support can be used effectively at the moment a stressful event occurs and/or when an individual is having a reaction to that stressful event. The authors identified the four social supports previously

mentioned and noted that these various supports can have a buffering effect when the support is most relevant for the stressors affecting the individual under stress. Cohen and Wills recommended further investigation to match between an individual's desires from a stressful event and what is available to that individual. Their recommendation encourages an exploration of the match–mismatch of social support that will be investigated in this study. Despite the fact that this recommendation was made in 1985, studies including social support mismatch as a variable in MS remain limited.

Social Support in Multiple Sclerosis

Social support is a one factor that has been found to affect anxiety and depression in MS. Mohr and colleagues (1999) aimed to examine patients' experiences of psychosocial changes as a result of having MS, in particular RRMS. First, the authors posed open-ended questions to 50 participants (66% women, 34% men) with an average age of 40 years old and from their answers pieced together 67 statements. An additional 94 participants (74.5% women, 25.5% men) with an average age of 42.6 years old then completed a rating of the 67 statements as well as assessments on physical functioning, neuropsychological functioning, depression, anxiety, anger, and ways of coping, which included confrontive, distancing, self-controlling, social support seeking, and others. The team categorized the patients' experiences of psychosocial changes as follows: demoralization, deterioration in relationships, and benefit-finding. They described demoralization as distress, loss of self-esteem, and alienation. Deterioration of relationships was characterized by patients feeling they are treated like victims and a sense of inadequacy in their relationships due to MS. While these two categories are reflective of more negative consequences, Benefit-finding was viewed as improvement of relationships with others, an appreciation for life, and increased spirituality. The authors primarily spoke about benefitfinding, as they found significant improvement in mental health related to this category, in particular, improvements with anxiety and anger. Benefit-finding was also significantly linked to seeking of social support. Depression was significant within the categories of demoralization and deterioration of relationships. It should be noted, as the authors themselves do, that this study should be replicated for these three categories, in the MS-specific measure created. This information is helpful in treating patients and can be a good starting point for future studies. Social support overall in this study had positive effects on anxiety, as when participants felt their relationships were improving, anxiety decreased, and it was noted that in viewing relationships as deteriorating, depression increased. Since this study, these results of the effects of social support on depression have been further supported.

A study conducted by Rommer and colleagues (2017) aimed to gain insight on mechanisms of coping and social support and to explore the relationships between level of impairment and coping behaviors on depression in 243 individuals with MS. The individuals in this study had an average age of 44 years old, and of the participants enrolled, 72.8% of them identified as female. Fifty-six percent of the participants had been diagnosed with RRMS, while 37% had SPMS, and 6.25% reported having PPMS. The results revealed that coping behavior was connected to social support, more specifically support given by family, friends, and other individuals with MS. Additionally, they found that social support was needed in individuals who were in more advanced stages of MS; however, they did not discuss how social support related to the levels of depression in the participants. To measure depression, they utilized the Beck Depression Inventory (BDI). Using the BDI is a limitation, as some somatic depressive symptoms are similar to symptoms of MS. For example, the BDI asks about feeling tired, but most individuals with MS suffer from MS fatigue. This is important to acknowledge, and it is important to utilize scales for mood and depression that look at non-somatic symptoms such as the HADS.

Rosiak and Zagożdżon (2018) sought to analyze "an association between specific forms of MS, subjectively perceived quality of life and social support" (p. 925). However, the social support scale they utilized only measured emotional support and instrumental support, leaving out two other known types of social support, informational/guidance and appraisal/feedback (Barrera & Ainlay, 1983; Glanz et al., 2008; Stokes & Wilson, 1984). The scale additionally claims to measure perceived and received social support separately; however, as the patients were the ones filling out the scale, this measure may be limited as a representation of the support they actually "received" as there is no way to measure what they truly received from their social support systems. Participants in this study with PPMS were four times more likely than those with RRMS to report a deterioration with quality of life. Overall, PPMS individuals had lower physical and psychological health scales and lower social health scales. The results regarding social support were not significant, but the authors stated that "our findings imply that support seeking is particularly important in the case of primary-progressive MS" (p. 931). This study seemingly attempts to address similarly the match-mismatch of social support; however, the authors were unable to do that due to several limitations including lack of survey completion.

Dennison et al. (2009) reviewed 72 studies in attempts to address psychological factors that may explain the adjustment outcomes in MS. Through their review they found evidence that social support and interactions with others predicted adjustment outcomes in MS. More specifically, they found that positive evaluations of the social support were connected with better adjustment outcomes. The authors encouraged future researchers to explore patients' expectations of those in their social lives. This recommendation for future studies is something that can be addressed through the present study, as the expectations they refer to are akin to the desired social support that was measured.

Stapleton et al. (2017) completed a meta-analysis on studies that measured social influence (social support) and measure of physical activity on individuals with physical disability, including MS and other chronic conditions that lead to physical disability. Overall, their results illustrated a positive relationship between social influence and physical activity among individuals with physical disability, with the magnitude of the effect being small- to medium-sized. In exploring the differences between the participants, they also found a stronger correlation between social influence and physical activity for those with a spinal cord injury than those with MS. The authors speculated that due to the progressive nature of MS that social influence or social support may not be as constant over time as it is for those with spinal cord injuries, because the patients' abilities change. They further suggested that those with greater mobility challenges may benefit more from social influence. With this in mind, it is important to explore the differences between the subtypes of MS in terms of desire and need for social support in this exploration.

Tough et al. (2017) reviewed 63 studies that examined social relationship constructs such as social support, social networks, negative social interactions, and relationship quality, and how these related to mental health of individuals with physical disabilities. In their search, they looked at studies that addressed health conditions that lead to physical disability, such as MS, spinal cord injury, stroke, rheumatoid arthritis, and Parkinson's disease. In order to ensure quality of the studies, they assessed each individually. In terms of social support, they reviewed 58 studies that looked at all four different types of social support, as well as different sources of social support. After reviewing results, a majority found an association between social support and mental health, while three had nonsignificant findings, two showed no association at all, and seven did not test the association. When reviewing the studies, however, the authors admittedly noted it was difficult to separate and compare studies that measured social support in their own way, for example, "assessing received support alongside those assessing perceived support" (Tough et al., 2017, p. 14). For this reason, it is necessary to clarify the measurement of social support such as perceived social support, desired social support, and satisfaction with social support.

As MS can be physically debilitating, many are interested in the relationship between physical disability and social support. Other diseases and medical conditions can also result in physical disability, and many times MS is observed in studies with these other illnesses and conditions. In their longitudinal study, De la Vega and colleagues (2018) had three hypotheses:

(1) the amount of perceived social support would be similar across individuals with different diagnoses often associated with disability (i.e., MS, spinal cord injury, muscular dystrophy), but (2) lower among men, relative to women, and (3) changes over time in perceived social support would be negatively associated with changes in depressive symptoms across diagnostic groups. (p. 1)

Of their 475 participants, 42% were diagnosed with MS. In terms of their second hypothesis, they did not find any difference between men and women, which is not consistent with previous literature. They reported that over time those who lost social support over the course of the study reported higher levels of depression than the individuals who reported gaining more social support; however, the majority of participants did not report social support changes. In fact, 78% of the participants did not experience significant social support changes from time one to time two. With this in mind, these results cannot necessarily be generalized to the MS population, as

there was no separation between chronic illnesses in the analyses for social support.

Additionally, they did not acknowledge the different types of social support and how different illness may require the different types. As previously studies have noted, those with spinal cord injury may have different needs over those with MS, due to the fact that MS is progressive and over time their social support needs change (Stapleton et al., 2017). In the end, the authors noted that that it is important to assess the desired social support. The authors also recommended evaluating psychological health as well as social networks and support in these individuals to develop interventions to strengthen and improve these factors.

Kasser and Kosma (2018) examined the role of physical activity in mobility impairment and further explored the social cognitive factors of social support, outcome expectations, and self-efficacy that facilitate physical activity among those with MS. The authors measured social support utilizing a scale that rates social support surrounding exercise behaviors, which could be viewed as instrumental support. Using information from over 319 individuals with MS, the authors discovered that one of the most important predictors of health-promoting levels of physical activity was social support. They broke it down further and identified that friends were a stronger indicator of social support than family. However, it is important to note that the authors implied that their findings were related to social support in general, when in fact they measured a more limited form of support.

Linden and Vodermaier (2012) explored the importance of social support and its association with emotional distress in cancer patients in comparison to a "healthy" group of individuals without cancer. The hypotheses of this study included that "when a match of need and availability for support is achieved, then distress is relatively low" (p. 1450), "when desire for support is high, but perceived availability is low, then distress is elevated" (p. 1450), and

when little support is perceived as available and there is a simultaneously low desire for support, then distress is also low" (p. 1450). This study sought to explore the match–mismatch model, which posits that even among those who have low perceived support, there are two subgroups involved, and those are those who desire more support and those who do not desire more. The study utilized a 21-item scale entitled the Psychosocial Screen for Cancer (PSSCAN), which has been validated for use with healthy populations as well as cancer population and those with other chronic diseases (Linden et al., 2009). Using a hierarchical linear regression, they tested their hypothesis of interaction effects of perceived and desired support and the impacts on anxious and depressive symptoms. The findings were aligned with those of the match–mismatch model as the cancer patients who perceived low support, but had a high desire for support had scores with the high levels of anxious and/or depressive symptoms, indicating a possible disorder. The other patients did not show clinical symptoms. Linden and Vodermaier inspired the exploration of social support and anxiety and depression in the MS population. The goal is to explore the importance of social support and its association with emotional distress in patients with MS.

Reynolds and Perrin (2004) wished to explore the mismatch of social support focusing on women with breast cancer and how a mismatch in social support can affect psychosocial adjustment. To do this they categorized the support as the following: positive congruent, support omission, support commission, and null support. Positive congruent support meant that the individual wanted a certain support and received it. Support omission meant that the individual wanted a certain support but did not receive that support. Support commission meant that the individual did not want a certain support but received that support. Lastly, null support meant that the individual did not want and did not receive a certain type of support. To measure this, Reynolds and Perrin used the Inventory of Socially Supportive Behaviors; however, they revised the method of scoring to measure both received and wanted social support separately. In addition to this, they also asked about the satisfaction of each support item. They additionally used a separate assessment to measure psychosocial functioning. Their findings, with data from 79 participants, illustrated that the match between the type of support a woman wants and what she receives plays a role in psychosocial functioning. Findings revealed that more commissions were associated with psychosocial adjustment, showing that while an individual may receive a lot of social support, they do not benefit from that support if they do not want it. Surprisingly, positive congruent support did not predict psychosocial adjustment. The authors stated, "Therefore, the match on unwanted items was more important to psychosocial adjustment than the match on wanted items" (p. 428). Examining the differences in the support actions wanted, the authors claimed that due to the differences in the actions wanted, results did not provide a clear support pattern associated with better or worse psychosocial adjustment. It is not yet known whether these findings will generalize to the MS population, whose chronic illness presents challenges that differ from those faced by cancer patients.

In 2019, Henry and colleagues sought to examine the relationship between perceived social support and anxiety and depression in individuals with MS. This was inspired after previous research had indicated that anxiety predicted depression in those with MS. These researchers attempted to take it a step further, and using a path analysis they addressed the relationship between perceived social support and anxiety and depression in MS. They also examined the effects of fatigue and disability and additionally considered the source of support looking at relatives, friends, and significant others. While their findings suggest that perceived social support from friends reduces anxiety symptoms, which in turn reduces depressive symptoms, social support from family had no effect on anxiety or depression. This finding may

be due to a limitation of the social support scale utilized for this particular study. The scale employed terminology with broad meanings, possibly resulting in heterogenous responses by participants. Additional limitations include a reported small sample size of 110, which required a bootstrap analysis. The small sample size also prevented comparison of the MS subtypes, which could have important clinical implications. Lastly, the authors failed to consider the desired support of the participants, as they only examined the perceived support. This is an important consideration due to the fact that not all patients desire more social support than what they currently receive. With these limitations in mind, one goal of the present study was to recruit a larger sample to increase the probability of having representation from the different MS subtypes.

Through a review of the literature, it can be seen that many studies are lacking when it comes to observing social support in the MS population. A gap within the literature is the comparison of MS subtypes in studies of social support, as only one study was able to find a difference (Rosiak & Zagożdżon, 2018). Further, in reviewing studies addressing social support in physical disability, Tough et al. (2017) noted that the measurement of social support varied widely, thus making comparison difficult. Most studies do not assess whether the participants actually desired the support that they received. The present study measured both perceived social support and desired social support. Linden and Vodermaier (2012) and Reynolds and Perrin (2004) both served as models for this study as they studied the match–mismatch of social support for their respective populations. The present study also adopted the definitions used by Reynolds and Perrin (2004) for types of match and mismatches of social support: positive congruent, support omission, support commission, and null support.

Chapter III

Methodology

The purpose of this chapter is to describe how the study was conducted. The chapter will elaborate on the population of interest and how the participants were recruited. The chapter further provides a description of the measurement instruments along with the reliability and validity, study design, hypothesis testing, and statistical analyses.

Population of Interest

The ultimate purpose of this study was to explore the relationship between social support, both desired and perceived, and symptoms of anxiety and depression. This study's aim was to also determine if a mismatch with perceived and desired social support will impact anxiety and depression in women with MS. In addition, the study sought to find any significant differences between the two most common MS subtypes, RRMS and PPMS.

While MS can be diagnosed in all persons, women are three times more likely to have MS than men (Harbo et al., 2013; Miclea et al., 2019; Sutton, 2017). Therefore, one of the inclusion criteria was the female gender. Participants were all consenting age, 18 years old, or older to participate in the study. All participants reported having a formal diagnosis of either relapsing-remitting multiple sclerosis or primary progressive multiple sclerosis by a neurologist. Participants were recruited through online posting on the National Multiple Sclerosis Society website where they were free to open the link with the survey at their convenience. They also were recruited through posting the National MS Society's website on social media outlets. To ensure statistical power, an a priori power analysis was completed to determine the sample size required for this study. Results of the power analysis indicated that 98 participants are needed to conduct a multivariate analysis of variance (MANOVA) with a medium effect size (.15), $\alpha = .05$, power = .80 (Faul et al., 2009).

Procedure

The survey was posted by the manager of research information for the National Multiple Sclerosis (MS) Society on the society's website. Individuals with MS were able to access the link to the survey. Upon clicking the link, a letter of solicitation appeared on the screen listing the purpose of the research, the procedures and voluntary nature of the survey, the anonymity and confidentiality, anticipated risks and discomfort, benefits to the research, and contact information. The survey contained the instruments, which was administered online using Qualtrics. The participants were able to complete the survey on any computer, smartphone, or tablet with Internet access at their own convenience and at a location of their choice. This study was conducted through anonymous surveys. Qualtrics indicates that their servers are protected by high-end firewall systems, and vulnerability scans are performed regularly (Oualtrics, 2018). Qualtrics reports that it deploys the general requirements set forth by many federal acts including the (FISMA) Act of 2002. All client data are considered confidential, and treated as such, with no specific designation. By using secure and certified data centers, Qualtrics ensures the highest protection and testing as per (HITECH) requirements (Qualtrics, 2018). The data in this study were collected through Qualtrics in order to protect subjects' anonymity. Information and data received from the Qualtrics system was stored on a USB memory key, which will be kept in a locked, secure location in the principal investigator's office. Only Elena Thomopoulos and her advisor, Dr. Pamela Foley, will have access to this information. This information will be safely stored until 5 years after the completion of the project, after which the data will be erased.

Participants gained access to the web survey on Qualtrics through a unique link. Upon opening the link, participants viewed a letter of solicitation (Appendix A), which stated that by completing the survey, participants were consenting to participate in the study. Upon consenting, a statement appeared to ask participants to affirm that they meet the inclusion criteria for participation in the study including that they are 18 years or older, a woman, and they have been formally diagnosed with MS. Once they affirmed the statement, by clicking "yes," they were instructed to continue to the survey. If they did not affirm this statement, and clicked "no," they were brought to a screen thanking them for their time, ending their access to the survey. Those who affirmed the statement proceeded on to complete a demographics portion of the survey. Participants then completed the Inventory of Socially Supportive Behaviors (ISSB), SymptoMScreen, and the Hospital Anxiety and Depression Scale (HADS).

Instruments

Demographic Questionnaire

The demographic questionnaire (Appendix B) was created specifically for this study. The information asked was age, age of diagnosis, marital status, race/ethnicity, employment status, state they currently reside in, type of MS, and if they are under current treatment and under the care of a neurologist.

Inventory of Socially Supportive Behaviors (ISSB)

The ISSB is a 40-item measure that was designed to assess the amount and type of help that is received from the helping systems surrounding an individual. For the sake of this study, however, the scoring of this instrument was modified, with permission granted by the creator, Dr. Manual Barrera (Appendix C). The ISSB was used, and part of the scoring was modeled after a previous study by Reynolds and Perrin (2004). These authors also were looking to measure the mismatches in social support, but in women with breast cancer. To accommodate the questions and hypotheses, they instead asked participants "yes" or "no" to each of the following questions, "Does your support person do this?" and "Do you want your support person to do this?" in reference to the items on the ISSB (Reynold & Perrin, 2004, p. 426). This method of scoring allows for an understanding of the types of social support participants want and what they believe they receive. Using Reynolds and Perrin (2004) as guidance, the scorings will indicate which type of matched or mismatched social support each participant has reported as follows: 1) positive congruent, 2) support omission, 3) support commission or, 4) null support. Additionally, the authors asked a satisfaction question on a Likert scale for each of the 40 items on the ISSB (Reynolds & Perrin, 2004). This additional question was not added to the survey due to the length of the overall survey with the other scales included.

The ISSB has an internal consistency reliability that has been consistently above .90 for the original measure, and the internal consistency for the abbreviated scale is .84 (Barrera et al., 1981; Barrera & Baca, 1990; Barrera et al., 1981; Cohen & Hoberman, 1983; Cohen et al., 1984; Stokes & Wilson, 1984). Research has supported the usefulness of the ISSB as a measure of social support, as it has been proven to be a psychometrically sound measure (Stokes & Wilson, 1984). The ISSB's test–retest reliability over a 2-day period was .88 (Barrera et al., 1981). The test–retest reliability over a month-long interval was 0.80 (Barrera & Ainlay, 1984).

SymptoMScreen

The SymptoMScreen (Appendix D) is a rapid assessment of symptom severity for MS. This tool was created in order to provide patients a means by which to convey to their physicians efficiently the severity of their symptoms across multiple domains by remaining less than a page long (Green et al., 2016). This scale consists of 12 functional domains identified by the authors including: mobility, dexterity, spasticity, body pain, sensation, bladder function, fatigue, vision, dizziness, cognition, depression, and anxiety. The scale utilizes a 7-point Likert scale from 0 = *not affected at all* to 6 = *total limitation/I'm unable to do most daily activities* (Green et al., 2016). An example of an item from the SymptoMScreen would be "Dizziness (Feeling off balance, 'spinning'/vertigo)," (Green et al., 2016, p. 3).

The SymptoMScreen has been validated on MS patients, 81% of whom were female, and 85% of whom had RRMS. In order to assess both criterion and construct validity Spearman rank correlations were conducted between the Performance Scales, a self-report measure for symptom severity in MS, which has been found to have good criterion and construct validity but has differences such as length and the use of 6-point scales (Green et al., 2016; Marrie & Goldman, 2007). The composite scores for SymptoMScreen correlated strongly with the combined Performance Scales scores. In addition, subscores for the SymptoMScreen also correlated strongly with the criterion measures of the Performance Scales (Green et al., 2016). Test–retest reliability was found to be excellent for SymptoMScreen (r = 0.71-0.94, p < .0001).

Hospital Anxiety and Depression Scale (HADS)

The HADS is a 14-item scale that was created to detect "states of depression and anxiety in the hospital medical outpatient clinic" (Zigmond & Snaith, 1983, p. 361). The two subscales within the HADS are meant to measure anxiety and depression separately. Individuals are asked to rank on a 5-point scale (0–4; Zigmond & Snaith, 1983). An important aspect of the HADS is that it does not ask about somatic symptoms or complaints. This is vital, as many of the participants may have somatic symptoms that could be explained by their illness or condition rather than anxiety or depression or vice versa. It is important that the questions asked focus on the psychological symptoms over the physical ones, which is what the HADS achieves.

The HADS has been validated on a variety of populations, including those within a primary care setting, the geriatric population, individuals diagnosed with cancer, stroke, and other diseases and illnesses (Davies et al., 1993; el-Rufaie & Absood, 1995; Honarmand & Feinstein, 2009; Ibbotson et al., 1994; Johnson et al., 1995). This is also true of the MS population (Honarmand & Feinstein, 2009). In reviewing the MS literature, the HADS is the most common and gold standard to measure anxiety and depression in individuals with MS. It is often cited and used in a variety of studies for individuals with MS when seeking to measure their anxiety and depression (Baron et al., 2011; Fiest et al., 2016; Forman & Lincoln, 2010; Gay et al., 2017; Henry et al., 2019; Lincoln et al., 2011; Mohr et al., 2005; Nordin & Rorsman, 2012; Sutton, 2017).

Through a review of 747 studies that utilized the HADS, Bjelland et al. (2002) separated the two sections of the HADS, the HADS-Anxiety and HADS-Depression, and analyzed the data from each published article. They found that correlations between the HADS-A and HADS-D had an average of .56, with a range of .40 to .74. The Cronbach's alpha for the HADS-A was an average of .83. The Cronbach's alpha for the HADS-D was an average of .82. They additionally found the sensitivity and specificity for both was about .80. The correlational studies revealed that the HADS, when compared to other questionnaires, ranged from .49 to .83 (Bjelland et al., 2002.)

Definition of Terms

Perceived social support: Perceived social support is an individual's assessment of the availability of the social support he or she is given (Roohafza et al., 2014). In this study, perceived social support was defined as the social support the recipient believes he or she is getting from a support person. For the purposes of this study, perceived social support was

measured through a yes or no response to the question, "Does your support person do this?" to each statement on the ISSB.

Desired social support: Desired social support is defined the social support needed by an individual (Linden & Vodermaier, 2012). In this study, desired social support was defined as the social support the recipient wants from his or her support person. For the purposes of this study, desired social support was measured through a yes or no response to the question, "Do you want your support person to do this?", to each statement on the ISSB (Reynolds & Perrin, 2004).

Positive congruent support: Positive congruent support is defined as a positive support where social support is wanted and received (Reynolds & Perrin, 2004). For the purposes of this study, positive congruent support was defined as the individual's report on the ISSB that she or he both wanted a certain support and received that support.

Support omission: Support omission is defined as social support is wanted but is not received (Reynolds & Perrin, 2004). In this study, support omission was defined as the individual's report on the ISSB that she or he wanted a certain support but did not receive that support.

Support commission: Support commission is defined as social support is not wanted, but it is received (Reynolds & Perrin, 2004). In this study, support commission is defined as the individual's report on the ISSB that she or he did not want a certain support but received that support.

Null support: Null support is defined as social support is not wanted, and it is not received (Reynolds & Perrin, 2004). For the purposes of this study, null support was defined as the individual's report on the ISSB that she or he did not want a certain type of support and did not receive that support.

Mismatched social support: Mismatched social support is defined as the misalignment of social support wanted and social support received (Reynolds & Perrin, 2004). For the purposes of this study, matched social support was defined as the participant desiring a certain level of social support and not receiving that level of social support. Mismatched social support, in this study, was either of the social support categories support omission or support commission.

Matched social support: Matched social support is defined as a match between the social support the individual wants and the social support he or she receives (Reynolds & Perrin, 2004). For the purposes of this study, matched social support was defined as the participant desiring a certain level of social support and receiving that level of social support. Matched social support can be either positive congruent or null support.

Anxiety: This study defined anxiety as having non-somatic anxious symptoms as measured by the Hospital Anxiety and Depression Scale.

Depression: For the purposes of this study, depression was defined as having any nonsomatic depressive symptoms as measured by the Hospital Anxiety and Depression Scale.

Study Design

The design of this study was non-experimental and cross-sectional. The purpose of this study was to determine if mismatched social support affects levels of anxiety and depression in individuals with MS. The variable of social support (i.e., congruent support, null support, support omission, support commission) served as the predictor, or independent variables, with depression and anxiety scores serving as the outcome, or dependent variables.

Hypotheses and Research Questions

Research Questions

The present study addressed the following questions:

1. How does degree of match in social support (i.e., support omission or support commission) affect anxious symptoms?

2. How does degree of match in social support (i.e., support omission or support commission) affect depressive symptoms?

3. Does the subtype of MS affect the level of depressive symptoms?

4. Does the subtype of MS affect the level of anxious symptoms?

Hypotheses

The hypotheses that were tested in this study are as follows:

1a. Participants who report support omission will report higher levels of anxious symptoms than those with positive congruent or null support.

1b. Participants who report support commission will report higher levels of anxious symptoms than those with positive congruent or null support.

2a. Participants who report support omission will report higher levels of depressive symptoms than those with positive congruent or null support.

2b. Participants who report support commission will report higher levels of depressive symptoms than those with positive congruent or null support.

3a. Participants who have PPMS will report higher levels of depressive symptoms than participants with RRMS.

4a. Participants who have PPMS will report higher levels of anxious symptoms than participants with RRMS.

Statistical Analyses

The analysis utilized in this study was a multivariate analysis of variance (MANOVA), which requires one or more categorical independent or predictor variable(s) as well as two or more continuous dependent or criterion variables. The predictor variable was social support. The criterion variables were depression and anxiety. For this study, the subtype of MS has two levels, RRMS and PPMS. Social support has four levels, including support commission, support omission, positive congruent support, and null support.

Hypothesis Testing

The following are the hypotheses that were tested in the current study along with a description of the statistical analysis that was used to test each hypothesis.

The first set of hypotheses focus on the effects of the different types of social support on anxious and depressive symptoms.

1a. Participants who report support omission will report higher levels of anxious symptoms than those with positive congruent or null support.

1b. Participants who report support commission will report higher levels of anxious symptoms than those with positive congruent or null support.

2a. Participants who report support omission will report higher levels of depressive symptoms than those with positive congruent or null support.

2b. Participants who report support commission will report higher levels of depressive symptoms than those with positive congruent or null support.

A one-way MANOVA was conducted to test the hypothesis that the population means for the dependent variables, anxious and depressive symptoms, are the same for all levels of a factor, across all groups, Null Support, Positive Congruent, Support Omission, Support Commission. In addition, a second one-way MANOVA was completed where the social support categories were broken into two levels, instead of four, matched social support and mismatched social support. To determine whether participants who have a match in social support (i.e., null support or positive congruent) would report lower anxious and depressive symptoms than those who have a mismatch in social support (i.e., support omission or support commission), two independent-sample t tests were conducted.

The second set of hypotheses considered the two main different types of MS and the differences in severity of depressive and anxious symptoms.

3a. Participants who have PPMS will report higher levels of depressive symptoms than participants with RRMS.

4a. Participants who have PPMS will report higher levels of anxious symptoms than participants with RRMS.

To determine whether participants who have been diagnosed with PPMS report more depressive symptoms and anxious symptoms versus those diagnosed with RRMS, two independent-sample *t* tests were conducted.

Chapter IV

Results

The focus of this chapter is to provide the results of the statistical analyses of the current study. Sample demographics, descriptive statistics, tests of hypotheses, supplementary analyses, and a summary of all of the findings are offered.

Sample Demographics

As previously mentioned in Chapter III, participants were recruited through the National MS Society's website as well as the sharing of the society's website on social media outlets. A total of 149 women started the survey; however, not all participants continued with the survey to the end. The final number was 103 participants. While there was a final number of participants, it should be noted that all 103 participants did not complete every item in the survey.

The participants in this study had an age range from 23-79 (M = 47.0, SD = 14.0). The age range for participants when they were diagnosed ranged from 16-62 (M = 35.3, SD = 10.3) (Table 1). Of the 103 women, 89 (86.4%) reported they had been formally diagnosed with RRMS, 8 (7.8%) reported they were diagnosed with PPMS, and 6 (5.8%) reported not knowing their type of MS (Table 2). One-hundred and two participants reported their race (Table 2). The majority of participants identified as White (n = 86), 7 participants identified as Hispanic/Latina, 2 as Black/African American, 2 as Bi-Racial White and other, 2 identified as Bi-Racial White and Hispanic/Latina, 1 as Bi-Racial White and Black/African American. The remaining three identified themselves as "Other" or did not respond to this demographics question. Relationship status was answered by all participants with 12.6% (n = 13) identifying as single, 64.1% (n = 66) identifying as married/partnered, 13.6% (n = 14) identifying as divorced, 1% (n = 1) identifying as widowed, and 8.7% (n = 9) identifying as in a relationship (Table 2). One participant

abstained from answering about their employment status. Of those who responded, 31 (30.4%) reported that they are working full-time, 11 (10.8%) reported they are working part-time, 3 (2.9%) identified as a student, 12 (11.8%) reported they are currently retired, 14 (13.7%) reported being unemployed, 24 (23.5%) reported that are currently on disability, 1 (1%) reported being on medical leave, 3 (2.9%) identified that they are both retired and disabled, 1 (1%) reported that they are a student and working part-time, and 2 (2%) reported that they are retired but also working part-time (Table 2). The participants in this study were from all across the United States, and a few were from the European Union (Table 3).

Table 1

Current Age, Age Diagnosed, and Years with MS

	М	SD	Range
Age Diagnosed	35.33	10.27	16-62
Current Age	46.96	13.93	23-79
Years with MS	11.63	10.68	0-41

Note. N = 103

Descriptive Statistics

Means, standard deviations, and ranges for entire sample for the HADS Anxiety, HADS Depression, and SymptoMScreen are as follows: HADS Anxiety M = 10.14, SD = 2.54, 4–16; HADS Depression M = 8.37, SD = 1.82, 3–14; SymptoMScreen M = 1.91, SD = 0.92, 0.17–4.50.

The SymptoMScreen Composite scores revealed that 30.1% of participants endorsed having very mild limitations due to their MS symptoms, 41.7% endorsed having mild limitations, 20.4% endorsed having moderate limitations, 6.8% endorsed having severe limitations, and 1% endorsed having very severe limitations.

The results from the entire sample for the ISSB are as follows: 13 individuals (12.6%)

falling under null support, 16 (15.5%) falling under support omission, and 74 (71.8%) falling under positive congruent (Table 4). It is important to note that no participants were found to be in the category of support commission. In breaking it down between matched and mismatched, 84.5% fell into matched social support, and 15.5% fell into mismatched social support (Table 5).

Variable	n	%
MS Subtype		
RRMS	89	86.4
PPMS	8	7.8
Other	6	5.8
Race		
White/Caucasian	86	84.3
Hispanic/Latina	7	6.9
Black/African American	2	2
Bi-Racial: White & Other	2	2
Bi-Racial: White & Hispanic/Latina	2	2
Bi-Racial: White & Black/African A	1	1
Other	2	2
Relationship Status		
Single	13	12.6
Married/Partnered	66	64.1
Divorced	14	13.6
Widowed	1	1
In a Relationship	9	8.7
Employment Status		
Full-Time	31	30.4
Part-Time	11	10.8
Student	3	2.9
Retired	12	11.8
Unemployed	14	13.7
Disability	24	23.5
Medical Leave	1	1
Retired & Disabled	3	2.9
Student & Part-Time	1	1
Retired & Part-Time	2	2

Table 2

Note. N = 103 for MS type. N = 102 for Race. N = 103 for

Relationship Status. N = 102 for Employment Status

Table 3

Geographic Location of Participants

Location	n	%
Arizona	2	0.1
California	2	0.1
Colorado	1	< 0.1
Connecticut	1	< 0.1
Washington DC	1	< 0.1
European Union	3	0.1
Florida	4	0.1
Georgia	1	< 0.1
Illinois	4	0.1
Indiana	1	< 0.1
Kentucky	1	< 0.1
Massachusetts	5	0.2
Maryland	2	0.1
Maine	1	< 0.1
Michigan	1	< 0.1
Minnesota	2	0.1
Missouri	3	0.1
North Carolina	5	0.2
New Hampshire	1	< 0.1
New Jersey	25	0.8
New Mexico	1	< 0.1
New York	8	0.3
Ohio	1	< 0.1
Oregon	3	0.1
Pennsylvania	6	0.2
Tennessee	1	< 0.1
Texas	2	0.1
Virginia	12	0.4
Vermont	1	< 0.1
Washington	2	0.1

Note. N = 103

Table 4

Social Support Categories

	п	%
Support Commission	0	0
Null Support	13	13
Support Omission	16	16
Positive Congruent	74	72

Note. N = 103

Table 5

Mismatch/Match Social Support

	п	%
Mismatch	16	16
Match	87	84

Note. N = 103

Tests of Hypotheses

The first set of hypotheses focused on the different types of social support and their effects on anxious and depressive symptoms. The first two hypotheses, 1a and 1b, predicted that participants who reported support omission and support commission would have higher levels of anxious symptoms than would those who reported positive congruent and null support. The second two hypotheses, 2a and 2b, predicted that participants who reported support omission and support commission would have higher levels of depressive symptoms than would those who reported positive congruent and null support. To explore these hypotheses, a one-way MANOVA was completed. The null hypothesis was that the means for the HADS Anxiety and HADS Depression scores were the same for all four levels of social support. The test for homogeneity of dispersion matrices was found to be nonsignificant, F(6,10738) = .841, p = .54. The results of the Wilks' lambda multivariate test was significant F(4, 198) = 2.93, p = .023 (Table 6). Breaking the results down further, the univariate ANOVAs for Depression scores was nonsignificant, F(2, 100) = 1.65, p = .198, while for Anxiety scores it was significant, F(2, 100) = 4.57, p = .013 (Table 7).

The second one-way MANOVA was conducted to examine the social support categories as two (i.e., mismatched and matched social support) over four. The test for homogeneity of dispersion matrices was found to be nonsignificant, F(3, 9126) = 1.296, p = .274. The results of the Wilks' lambda multivariate test was significant, F(2, 100) = 4.752, p = .011 (Table 8), indicating that there was a difference between the two social support categories. Similar to the first MANOVA, the univariate ANOVA for Depression scores was nonsignificant, F(1, 101) = 0.834, p = .363, while for Anxiety scores it was significant, F(1, 101) = 9.145, p = .003 (Table 9).

Table 6

MANOVA with four levels of Social Support

		Value	F	Hypothesis df	Error df	р	η^2
Social Support Categories	Wilks' Lambda	0.891	2.93	4	198	.022*	0.056

Note. Dependent Variabes are HADS Anxiety Score and HADS Depression Score. *p < .05. **p < .01.

Table 7

Tests of Between-Subjects Effects: ANOVA for HADS Anxiety Score and ANOVA for HADS Depression Score with four levels of Social Support

	Dependent Variable	df	Mean Square	F	р	η^2
Social Support Categories	HADS Anxitey	2	27.54	4.56	.013*	0.084
	HADS Depression	2	5.12	1.58	.212	0.031

p < .05. p < .01.

Two independent-sample *t* tests were then completed to investigate these hypotheses further. Of the 103 participants, none reported support commission, so the four social support categories were then identified as either matched social support (i.e., null support or positive congruent) and mismatched social support (i.e., support omission). The first independent-sample *t* test that looked at the depressive symptoms was nonsignificant, t(101) = -0.913, p = .363 (Table 10). The second independent-sample *t* test looked at the anxious symptoms and was found to be significant, t(101) = 3.02, p = .003 (Table 10). The results, however, were counter to the research hypothesis. Participants who had a match in social support (M = 10.45, SD = 2.50), were more anxious than those with a mismatch in social support (M = 8.44, SD = 2.06) (Table 10). The 95% confidence interval for the difference in means ranged from 0.69 to 3.33. With these results, we are 95% confident that the true mean difference between match and mismatch social support in terms of the amount of their anxious symptoms is going to be at least 0.69 and up to 3.33.

Table 8

		Value	F	Hypothesis df	Error df	р	η^2
Match/Mismatch	Wilks' Lambda	0.913	4.75	2	100	.011*	0.087

Note. Dependent Variabes are HADS Anxiety Score and HADS Depression Score. *p < .05. **p < .01.

Table 9

Tests of Between-Subjects Effects: ANOVA for HADS Anxiety Score and ANOVA for HADS Depression Score with two levels of Social Support

	Dependent Variable	df	Mean Square	F	р	η^2
Match/Mismatch	HADS Anxitey	1	54.64	9.15	.003**	0.083
	HADS Depression	1	2.75	0.83	.363	0.008

p < .05. p < .01.

The second set of hypotheses, 3a and 4a, focused on the two main types of MS, RRMS and PPMS, to determine whether either is associated with a higher level of depressive or anxious symptoms. The hypotheses predicted that participants with PPMS would report higher levels of both depressive and anxious symptoms than participants diagnosed with RRMS. To explore these predictions, two independent-sample *t* tests were conducted. The tests revealed to be nonsignificant for both anxious symptoms, t(95) = -1.73, p = .087, and depressive symptoms, t(95) = 1.22, p = .225 (Table 11).

Table 10

Independent-Sample t tests Comparing Anxious & Depressive symptoms in Matched & Mismatched Social Support

	Ma	Match		Mismatch		р
	М	SD	М	SD		
HADS Anxiety	10.45	2.5	8.44	2.06	3.02	0.003**
HADS Depression	8.3	1.85	8.75	1.61	-0.913	.363

p* < .05. *p* < .01.

Supplementary Analysis

The above results suggest that anxious symptoms are significantly affected by social support in women with MS. To take this a step further, a bivariate correlation was completed to look at the relationship between MS symptoms and anxious symptoms. The correlation used the composite score of the SymptoMScreen and HADS Anxiety score and was found to be significant, r(101) = -0.30, p = .002. This shows a small to moderate negative relationship between the severity of MS symptoms and anxious symptoms.

Table 11

	RR	MS	PP	MS	t(95)	р
	М	SD	М	SD		
HADS Anxiety	9.91	2.48	11.5	2.73	-1.73	.087
HADS Depression	8.46	1.88	7.63	1.41	1.22	.225

Independent-Sample t test Results Comparing Anxious & Depressive symptoms in different MS Subtypes

p < .05. p < .01.

Additional correlations were completed on each set of symptoms that SymptoMScreen measures in relation to anxious symptoms. Of the 10 symptoms SymptoMScreen accounts for, five of them have significant relationships with HADS Anxiety score. The following correlations were found to be significant: the correlation between the SymptoMScreen score on vision symptoms and HADS Depression score, the correlation between the SymptoMScreen score on vision symptoms and HADS Anxiety score, the correlation between the SymptoMScreen score on vision symptoms and HADS Anxiety score, the correlation between the SymptoMScreen score on hand function/dexterity and HADS Anxiety score, and the correlation between the SymptoMScreen score on hand function/dexterity and HADS Anxiety score, and the correlation between the SymptoMScreen score on hand function/dexterity and HADS Anxiety score, and the correlation between the SymptoMScreen score on hand function/dexterity and HADS Anxiety score, and the correlation between the SymptoMScreen score on hand function/dexterity and HADS Anxiety score, and the correlation between the SymptoMScreen score on hand function/dexterity and HADS Anxiety score, and the correlation between the SymptoMScreen score on hand function/dexterity and HADS Anxiety score, and the correlation between the SymptoMScreen score on bodily pain and HADS Anxiety score (Table 12).

Previous research has suggested that a risk factor for anxiety in individuals with MS would be younger age and shorter disease duration (Hanna & Strober, 2020). With this in mind, a correlation between HADS Anxiety, the current age of participants, and the number of years

Table 12

Correlations between HADS Anxiety Score, HADS Depression Score, and each MS Symptoms Domain from the SymptoMScreen

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. HADS Anxiety Score	-													
2. HADS Depression Score	102	-												
3. Affects on Walking/Mobility	.056	029	-											
4. Affects on Head function/Dexterity	243*	028	.506**	-										
5. Affects on Spasticity & Stiffness	185	.109	.504**	.397**	-									
6. Affects on Bodily Pain	195*	.072	.451**	.433**	.572**	-								
7. Affects on Sensory Symptoms	086	.039	.466**	.470**	.426**	.720**	-							
8. Affects on Bladder Control	016	.108	.563**	.402**	.394**	.447**	.453**	-						
9. Affects on Fatigue	168	.019	.320**	.313**	.298**	.492**	.526**	.456**	-					
10. Affects on Vision	218*	.270**	.035	.231*	.102	.147	.209*	.173	.215*	-				
11. Affects on Dizziness	232*	036	.298**	.532**	.306**	.365**	.386**	.231*	.372**	.271**	-			
12. Affects on Cognitive Function	128	.151	.146	.280**	.335**	.399**	.376**	.362**	.533**	.215*	.370**	-		
13. Affects on Depression	378**	.218*	.191	.329**	.290**	.297**	.300**	.242*	.398**	.400*	.427**	.456**	-	
14. Affects on Anxiety	533**	.192	.125	.370**	.319**	.435**	.388**	.267**	.340**	.463**	.377**	.408**	.782**	-

p* < .05. *p* < .01.

they have been living with MS was computed. The correlation between HADS Anxiety and current age was significant at the .05 level, r(103) = 0.199, p = .043. There was no significance between HADS Anxiety score and the number of years with MS, r(103) = 0.130, p = .190.

In this study the majority of participants reported being from New Jersey (n = 25). The larger number of participants from this state was due to posts put on social media by the researchers, who primarily have connections to individuals in New Jersey as well as the National MS Society's support group in Northern New Jersey volunteered to share this survey with its members. An independent sample *t*-test was completed to compare the mean HADS scores for Anxiety and Depression between the participants from New Jersey and the rest of the participant pool. The results were nonsignificant, which means that the there was no significant difference between HADS scores of the New Jersey participants and the rest of the participants.

Summary

The results of this study were unexpected. While there were significant results between the effects of social support on anxiety, the findings were opposite of the predictions. To further investigate the relationship between anxious symptoms in these participants, correlations yielded additional surprising results, showing a mostly negative relationship between the severity of MS symptoms and anxious symptoms. One correlation revealed a positive relationship between vision symptoms and depressive symptoms. The findings surrounding the relationship between the type of MS an individual has and the anxious and depressive symptoms were nonsignificant. These results and their implications for clinical practice and future research are discussed further in Chapter V.

Chapter V

Discussion

The purpose of this chapter is to summarize and discuss the findings of this study and to consider the implications for clinical practice. The limitations of the study are also addressed, and areas for future research are identified.

Summary of Results of Hypothesis Testing

The first set of hypotheses, 1a, 1b, 2a, and 2b, had a primary focus on addressing the different types of support participants reported as well as their depressive and anxious symptoms. In completing the two MANOVAs, the results were found to be significant. Looking closer at the univariate ANOVAs for the Depression and Anxiety scores it was noted that the ANOVA for depressive symptoms was nonsignificant, while anxious symptoms was significant. Keeping in mind past studies, as discussed earlier on, it was not surprising that, at least, the analysis showed the relationship between social support and anxiety to be significant in women with MS (Feinstein et al., 1999; Gay et al., 2017; Gay et al., 2010; Korostil & Feinstein, 2007; Mohr et al., 1999; Roohafza et al., 2014). These results are surprising, as they counter the initial hypothesis as revealed by the independent-sample t tests. It was thought that participants who reported support omission and support commission would have higher levels of anxious symptoms, while those reporting null support and positive congruent support would have lower levels; however, the opposite was found. In past studies, findings have found that social support was found to have positive effects on anxiety (Feinstein et al., 1999; Gay et al., 2017; Mohr et al., 1999; Roohafza et al., 2014). Even still, previous studies have found similar findings in that even though individuals with MS were satisfied with their social support, they still reported having high rates of depressive and anxious symptoms (Gay et al., 2010).

The second set of analyses provided a closer look at individuals with the two most common types of MS, RRMS and PPMS, and how their reports of depressive and anxious symptoms may differ. Previous findings indicated that participants with PPMS might have higher levels of both depressive and anxious symptoms (Lorefice et al., 2015; Rosiak & Zagożdżon, 2018). While many studies have pointed to the idea that women with PPMS may be more likely to have depressive and anxious symptoms due to the severity of symptoms, effects on the brain, and progression of the disease, these results did not indicate this (Lotrich et al., 2011; Sutton, 2017). The results of the independent-sample *t* tests revealed to be nonsignificant.

Discussion of Results of Hypothesis Testing

This study revealed a significant relationship between social support and anxious symptoms. However, the nature of the relationship was surprising, as it is counter to the initial predictions. Initially, participants were identified within the four social support groups (i.e., positive congruent, null support, support omission, support commission). After the MANOVA revealed significant results, to explore more into the social support relationship, participants were then divided into two groups, matched social support, which consisted of null support and positive congruent, and mismatched social support, which consisted of support omission and support commission to further explore the relationship. The additional MANOVA indicated no significant effect for level of depression but that participants with matched social support were more anxious than those with mismatched social support. The independent-sample *t* tests showcased the surprise, showing that participants with matched social support were more anxious than those with mismatched social support.

The results of this study were unexpected due to the amount of past research conducted on similar relationships. For example, depression was nonsignificant and did not appear to have a strong relationship with anxiety. Gay and team (2017), when analyzing how anxiety affects coping, emotional processing, emotional balance, and depression in individuals with MS, discovered that anxiety was a strong predictor of depression via both direct and indirect pathways. With their findings, they concluded that anxiety affects depression through unregulated and negative emotions. While surprising, the results do reflect similar findings to those in other studies. They are consistent with findings by Fiest and colleagues (2016), as they evaluated the effectiveness of psychological and pharmacological treatments for depression and anxiety in individuals with MS. Their findings suggest that treatments for depression were more effective in reducing symptoms for those with MS, but they could not find sufficient evidence to support the same claim about anxiety. With this in mind, it is possible that participants may be more aware of depressive symptoms and have already sought treatment, but they may not have recognized their anxiety. As mentioned previously, many somatic symptoms of anxiety can be mistaken for illness or disease, which is possible for women with MS, which risks leaving it untreated (Beck Anxiety Inventory, Beck et al., 1988; Béthoux et al., 2013; Honarmand & Feinstein, 2009). Gay and colleagues (2010) emphasized that while their participants had a higher rate of depressive and anxious symptoms than they anticipated, the participants reported an overall satisfaction with their social support. The findings of Gay and team (2010) are more aligned with the findings of this study in that, while there was a matched level of social support, there were also high levels of anxious and depressive symptoms. Of the 103 participants in this study, 6 reported severe anxious symptoms, 39 reported moderate anxious symptoms and 11 reported moderate depressive symptoms, 44 reported mild anxious symptoms and 59 reported mild depressive symptoms, and 14 fell into the normal range of anxious symptoms and 33 fell into the normal range of depressive symptoms.

When looking at age in this study, findings revealed a significant positive correlation, indicating that participants who were older had higher levels of anxiety. These findings were contrary to those of Hanna and Strober (2020), as they reported that younger age was associated with higher levels of anxiety. Higher mental health symptoms with younger individuals are often seen clinically, possibly because as individuals age, they may have more experience with these issues and may be able to cope better. In these circumstances, however, it is possible that there were other factors at play, as discussed below. It can be also said that the duration of years with MS might have a correlation between anxious and depressive symptoms; however, in this study there were no significant findings related to this.

It is worth mentioning that at the time of data collection for the present study, the world was suffering through the COVID-19 pandemic. In these unprecedented times, all around the world individuals were in lockdown, separated from each other with little physical human contact. While the world was well-served by the use of video calling, this clearly cannot completely replace in-person human interaction. The concern for the world's mental health was a constant topic of conversation, a valid concern as many people remained isolated, and as a result sparked the idea for new research (Fountoulakis et al., 2021; Minihan et al., 2020; Robb et al., 2020; Salari et al., 2020; Varma et al., 2021). On top of this, the national exposure and awareness of structural racism following video evidence of several police-involved deaths of Black men and women that went viral during this time, with subsequent nationwide protests, as well as the Capitol insurrection on January 6, 2021, only added to the tension and stress on many individuals.

Studies all around the world have explored the effects the pandemic has played on mental health, in particular anxiety and depression (Fountoulakis et al., 2021; Salari et al., 2020). Özdin

and Bayrak Özdin (2020) found that the groups most psychologically affected by the pandemic included women and individuals with chronic disease. Studies have not found age differences in terms of how the pandemic has affected mental health, with many showing that the pandemic negatively impacted mental health in all age ranges (Robb et al., 2020; Varma et al., 2021). There is no doubt that there were many people who were suffering and vulnerable at this time. It is necessary to acknowledge the data of this study showed the majority of participants endorsed at least mild symptoms of both anxious and depressive symptoms. While many people were receiving social support in a variety of ways, it is possible they were unable to receive support in ways they needed, and with this in mind, the confounding effects of the pandemic cannot be ignored. The Centers for Disease Control and Prevention (CDC) published an article by Czeisler and colleagues (2020), which looked at symptoms of anxiety and depression, along with other vital mental health and behavioral components in adults (18+) in the United States. They concluded stating, "Markedly elevated prevalences of reported adverse mental and behavioral health conditions associated with the COVID-19 pandemic highlight the broad impact of the pandemic and the need to prevent and treat these conditions" (Czeisler et al., 2020, p. 1054). Taking into consideration the challenges many individuals faced at this time, the participants' mental health could have been negatively affected across the entire sample, which may have minimized differences between them.

The last two hypotheses and their subsequent analysis did not provide any additional insight into the differences between subtypes of MS and how they may impact an individual's anxious and/or depressive symptoms. This was a common finding in prior studies, as Henry and team (2019) highlighted the difficulty in finding participants with the varying subtypes of MS to examine their significant differences, which was true in this case (Kirchner & Lara, 2011).

Overall, the results from this study were not as expected. It is clear that there is a relationship between social support and anxious symptoms, but the findings from this study did not provide additional clarity.

Limitations

The study was not without its limitations in regard to the sample and method. Participants were self-selected to take this survey. A major limitation was the limited representation from the MS subtype PPMS. This made it difficult to detect any significant differences that may exist between these two subgroups; therefore, the results cannot be generalizable to all women with MS. An added limitation is that the sample included only women who were able to gain access to a computer, tablet, or smartphone with Internet access. The method of taking the survey also may have limited participation for those with dexterity issues. Likewise, it was beyond the scope of this study to measure all additional psychosocial variables such as socioeconomic status, religion, level of education, or other stressors that may impact an individual's mental health or social support.

The measures used for this study are all self-report, which poses an additional limitation. Participants were asked about their anxious and depressive symptoms and may over- or underestimate their symptoms. As mental health can be stigmatized, some participants many not want to admit they are experiencing symptoms and not answer the questions accurately. An additional limitation related to mental health is that the survey did not ask about nor assess pre-existing anxious or depressive symptoms, or mental health diagnoses.

Additionally, while the final number of participants was 103, all participants did not necessarily complete every item in the survey. For example, in the ISSB, some participants answered, "Does your support person do this?" but did not answer "Do you want your support

person to do this?" In this case that item was removed from the scoring and was unable to be taken into consideration as a contributing factor to categorizing a participant in their respective social support group. While this seems unusual, the creator of the ISSB, Dr. Manual Barrera, granted the ability to alter the scale as needed, including scoring and item removal (Appendix C).

The length of this survey was an added limitation and could have been responsible for some individuals to drop out. For example, due to the findings that the majority of the sample had mild or very mild symptoms, it is possible that those with more severe symptoms may have had more difficulty completing the study and may have opted not to participate or dropped out of the survey.

Finally, as noted above, an additional limitation to this study was the current state of the world in regards to the COVID-19 pandemic. This study was designed prior to the pandemic, and therefore the impacts of mental health could not have been predicted or necessarily accounted for beforehand. Therefore, it is possible the severity of anxious and depressive symptoms across the sample was increased due to the added stress of the pandemic. In addition to this, a limitation was the inability to properly assess the role the pandemic played on anxious and depressive symptoms.

Implications for Clinical Practice

In the world, there are about 2.3 million people diagnosed with MS. The nature of this neurological disease prevents the world from seeing the struggle many individuals with MS face every day because their symptoms are often invisible. With this in mind, when we think of mental health issues, these too, like MS symptoms, are invisible to the eye. This is important to keep in mind when treating and working with a woman with MS.

Women are three times more likely to be diagnosed with MS than men (Birnbaum, 2013; Sutton, 2017). In this study, the results reinforce the importance of addressing anxious and depressive symptoms in women with MS, as most women presented with at least mild symptoms of both anxious and depressive symptoms. It is important to take into consideration both physical and mental health in planning treatment. For many years there have been disparities in medical treatment for men and women. While there are many biases in health care disparities that are perpetuated due to race, age, ethnicity, SES, and many more factors, gender is a common factor across these categories (Alcalde-Rubio et al., 2020; Samulowitz et al., 2018). The majority of women endorsed mild-moderate limitations due to their MS symptoms and endorsed anxious and depressive symptoms. This information should reinforce the need for healthcare providers to continue to monitor for both physical and mental health symptoms when caring for a woman with MS.

The results of this study reinforce the importance of addressing anxious and depressive symptoms in women with MS, as the majority of participants presented with at least mild anxious and depressive symptoms. One could conclude from this information that an integration of mental health services within a medical healthcare setting would be beneficial. There is a shift throughout the country of reinforcing a stigma-free environment when it comes to mental health. Many hospitals are shifting to a whole health model, which includes attending to patients' mental health needs alongside their physical health. The population of individuals with MS is a primary example of the necessity for this integration. This integration of care, along with collaboration of healthcare workers, can create a more helpful and effective treatment center for patients, especially those with chronic illnesses and diseases.

The findings suggest a significant relationship between the severity of MS symptoms and anxious symptoms. This information is important for psychologists and any healthcare workers treating women with MS. This implies that it would be necessary to assess disease-related symptoms as well as mental-health-related symptoms. Due to the variability of MS and the changes that may occur over time such as flare-ups or an increase in severity of symptoms such as issues with vision, dexterity, and fatigue, healthcare providers should consider how the progression in symptoms may affect their patients' overall mental health needs, and in turn affect their social support needs. As the disease may progress, women may have different needs from their social supports including family members, friends, and healthcare providers. This message emphasizes the importance to women with MS not only to consider maintaining their physical health but their mental health.

Directions for Future Research

There is an abundant amount of research dedicated to MS and mental health; however, the results vary, and each study presents with its own set of limitations. Similar limitations of past studies were present in this study. The ability to study the different subtypes of MS and the potential differences in psychosocial variables, including anxious and depressive symptoms, should continue to be examined. Additionally, the role matched and mismatched social support plays on anxious and depressive symptoms on women with MS is still unclear. As stated previously, no previous studies were able to examine both perceived and desired social support in a defined manner. Social support has most often been measured in the form of perceived social support, or the assessment of the availability of social support that is reported by the participant (Roohafza et al., 2014; Rosiak & Zagożdźon, 2018). To further address the match and

mismatch of social support, the perceived social support and desired social support need to be further distinguished in future studies, similarly in this study.

While this study did not address the different types of social support (i.e., emotional support, instrumental support, informational/guidance, appraisal/feedback), the ISSB scale is representative of each type of social support and has been broken down by previous researchers and authors (Barrera & Ainlay, 1983; Glanz et al., 2008; Stokes & Wilson, 1984). The inability to further examine the different specific types of social support was due to the lack of full completion in each participant's survey. To break down the different types of social support an individual can provide would be an additionally interesting exploration. For women with MS, it would be interesting to examine if they would prefer more instrumental support or emotional support and how that may impact their mental health. A further aspect to consider would be the comparison of the types of social support women desire and whether that desire for support fluctuates during flare-ups or development of new MS symptoms. It also would be beneficial to consider if women with different types of MS would prefer different types of social support. The answers in these future studies may better prepare healthcare providers treating women with MS, and their caregivers.

Conclusions

The current study is unique in that it considered disease-related factors in conjunction with psychological and psychosocial factors that may shed light on improvement in care for women with MS. While the results provided significant findings, they were not what was expected. Regardless, this information added to the literature and encourages many new directions for future research. The population of women with MS showcase the importance of both physical and mental health and the call for healthcare professionals to work together for effective care. This study brings more awareness to women with MS and their invisible physical and mental health symptoms.

References

- Alcalde-Rubio, L., Hernández-Aguado, I., Parker, L.A. Bueno-Vergara, E., & Chilet-Rosell, E. (2020). Gender disparities in clinical practice: are there any solutions? Scoping review of interventions to overcome or reduce gender bias in clinical practice. *International Journal for Equity in Health*, 19(166). https://doi.org/10.1186/s12939-020-01283-4
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed., pp. 338–344). Author.
- American Psychiatric Association. (2016a). *Anxiety disorders: DSM-5*® selections. American Psychiatric Association Publishing.
- American Psychiatric Association. (2016b). *Depressive disorders : DSM-5*® selections. American Psychiatric Association Publishing.
- Baron, K. G., Corden, M., Jin, L., & Mohr, D. C. (2011). Impact of psychotherapy on insomnia symptoms in patients with depression and multiple sclerosis. *Journal of Behavioral Medicine* 34(2), 92–101.
- Barrera, M., Jr., & Ainlay, S. L. (1983). The structure of social support: A conceptual and empirical analysis. *Journal of Community Psychology*, 11, 133–143.
- Barrera, M., Jr., & Baca, L. M. (1990). Recipient reactions to social support: Contributions of enacted support, conflicted support, and network orientation. *Journal of Social and Personal Relationships*, 7, 541–551.
- Barrera, M., Jr., & Balls, P. (1983). Assessing social support as a prevention resource: An illustrative study. *Prevention in Human Services*, *2*(4), 59-74.

- Barrera, M., Jr., Sandler, I. N., & Ramsay, T. B. (1981). Preliminary development of a scale of social support: Studies on college students. *American Journal of Community Psychology*, 9, 435–447.
- Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*, 117(3), 497– 529. https://doi.org/10.1037/0033-2909.117.3.497
- Beck, A. T., Epstein, N., Brown, G., & Steer, R. A. (1988). An inventory for measuring clinical anxiety: Psychometric properties. *Journal of Consulting and Clinical Psychology*, 56, 893–897.
- Beiske, A. G., Svensson, E., Sandanger, I., Czujko, B., Pedersen, E. D., Aarseth, J. H., & Myhr,
 K. M. (2008). Depression and anxiety amongst multiple sclerosis patients. *European Journal of Neurology*, *15*, 239–245. https://doi.org/<u>10.1111/j.1468-1331.2007.02041.x</u>
- Benedict R. H. B., Hussein S., Englert J. et al. (2008). Cortical atrophy and personality in multiple sclerosis. *Neuropsychology*, 22, 432–441.
- Béthoux, F., Fox, R., & Rae-Grant, A. (2013). *Multiple sclerosis and related disorders: Diagnosis, medical management, and rehabilitation*. Demos Medical.
- Birnbaum, G. (2013). *Multiple sclerosis: Clinician's guide to diagnosis and treatment* (2nd ed).Oxford University Press.
- Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). *The validity of the Hospital Anxiety and Depression Scale. Journal of Psychosomatic Research*, *52*(2), 69– 77. https://doi.org/10.1016/s0022-3999(01)00296-3
- Boeschoten, R. E., Braamse, A. M. J., Beekman, A. T. F., Cuijpers, P., van Oppen, P., Dekker,J., & Uitdehaag, B. M. J. (2017). Prevalence of depression and anxiety in multiple

sclerosis: A systematic review and meta-analysis. *Journal of the Neurological Sciences,* 372, 331–341. https://doi.org/10.1016/j.jns.2016.11.067

- Butler, E., Matcham, F., & Chalder, T. (2016). A systematic review of anxiety amongst people with multiple sclerosis. *Multiple Sclerosis Related Disorders*, 10, 145–168. <u>https://doi.org/10.1016/j.msard.2016.10.003</u>
- Chwastiak, L., Ehde, D. M., Gibbons, L. E., Sullivan, M., Bowen, J. D., & Kraft, G. H. (2002).
 Depressive Symptoms and Severity of Illness in Multiple Sclerosis: Epidemiologic Study of a Large Community Sample. *The American Journal of Psychiatry*, *159*(11), 1862–1868.
- Cohen, L. H., McGowan, J., Fooskas, S., & Rose, S. (1984). Positive life events and social support and the relationship between life stress and psychological disorder. *American Journal of Community Psychology*, 12, 567–587.
- Cohen, S. (2004). Social relationships and health. *American Psychologist*, 59(8), 676–684. https://doi.org/10.1037/0003-066x.59.8.676
- Cohen, S., & Hoberman, H. M. (1983). Positive events and social supports as buffers of life change stress. *Journal of Applied Social Psychology*, *13*, 99–125.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98(2), 310–357. https://doi.org/10.1037/0033-2909.98.2.310
- Czeisler, M. É., Lane, R. I., Petrosky, E., Wiley, J. F., Christensen, A., Njai, R., Weaver, M. D., Robbins, R., Facer-Childs, E. R., Barger, L. K., Czeisler, C. A., Howard, M. E., & Rajaratnam, S. M. W. (2020). Mental health, substance use, and suicidal ideation during the COVID-19 pandemic United States, June 24–30, 2020. *Centers for Disease*

Control and Prevention: Morbidity and Mortality Weekly Report, 69(32), 1049–1057. https://doi.org/<u>10.15585/mmwr.mm6932a1external icon</u>

Davies, K. N., Burn, W. K., McKenzie, F. R., & Brothwell, J. A. (1993). Evaluation of the Hospital Anxiety and Depression Scale as a screening instrument in geriatric medical inpatients. *International Journal of Geriatric Psychiatry*, 8, 165–169.

Debouverie, M., Pittion-Vouyovitch, S., Louis, S., Roederer, T., & Guillemin, F.
(2007). Increasing incidence of multiple sclerosis among women in Lorraine, Eastern
France. *Multiple Sclerosis Journal*, *13*(8), *962–967*.
https://doi.org/10.1177/1352458507077938

- de la Vega, R., Molton, I. R., Miró, J., Smith, A. E., & Jensen, M. P. (2018). Changes in perceived social support predict changes in depressive symptoms in adults with physical disability. *Disability and Health Journal*. <u>https://doi.org/10.1016/j.dhjo.2018.09.005</u>
- Dennison, L., Moss-Morris, R., & Chalder, T. (2009). A review of psychological correlates of adjustment in patients with multiple sclerosis. *Clinical Psychology Review*, 29(2), 141– 153. https://doi.org/10.1016/j.cpr.2008.12.001
- el-Rufaie, O. E., & Absood, G. H. (1995). Retesting the validity of the Arabic version of the Hospital Anxiety and Depression (HAD) scale in primary health care. *Social Psychiatry Psychiatric Epidemiology, 30,* 26–31.
- Faul, F., Erdfelder, E., Buchner, A. & Lang, A. (2009). Statistical power analyses using
 G*Power 3.1: Tests for regression and correlation analyses. *Behavior Research Methods*,
 41(4), 1149–1160.
- Feinstein, A. (2002). An examination of suicidal intent in patients with multiple sclerosis. Neurology, 59(5), 674–678. https://doi.org/10.1212/wnl.59.5.674

- Feinstein, A., O'Connor, P., Gray, T., & Feinstein, K. (1999). The effects of anxiety on psychiatric morbidity in patients with multiple sclerosis. *Multiple Sclerosis Journal*, 5(5), 323–326. https://doi.org/10.1177/135245859900500504
- Feinstein, A., & Pavisian, B. (2017). Multiple sclerosis and suicide. *Multiple Sclerosis Journal*, 23(7), 923–927. https://doi.org/10.1177/1352458517702553
- Fiest, K. M., Walker, J. R., Bernstein, C. N., Graff, L. A., Zarychanski, R., Abou-Setta, A. M., Patten, S. B., Sareen, J., Bolton, J. M., Marriott, J. J., Fisk, J. D., Singer, A., & Marrie, R. A. (2016). Review article: Systematic review and meta-analysis of interventions for depression and anxiety in persons with multiple sclerosis. *Multiple Sclerosis and Related Disorders*, *5*, 12–26. <u>https://doi.org/10.1016/j.msard.2015.10.004</u>
- Forman, A. C., & Lincoln, N.B. (2010). Evaluation of an adjustment group for people with multiple sclerosis: A pilot randomized controlled trial. *Clinical Rehabilitation*, 24(3), 211–221.
- Fountoulakis, K. N., Apostolidou, M. K., Atsiova, M. B., Filippidou, A. K., Florou, A. K.,
 Gousiou, D. S., Katsara, A. R., Mantzari, S. N., Padouva-Markoulaki, M.,
 Papatriantafyllou, E. I., Sacharidi, P. I., Tonia, A. I., Tsagalidou, E. G., Zymara, V. P.,
 Prezerakos, P. E., Koupidis, S. A., Fountoulakis, N. K., & Chrousos, G. P. (2021). Self-reported changes in anxiety, depression and suicidality during the COVID-19 lockdown in Greece. *Journal of Affective Disorders*, *279*, 624–629. https://doi.org/10.1016/j.jad.2020.10.061
- Franco, M. (2014). Anxiety in MS: Frequently overlooked and undetected. Retrieved from https://mymsaa.org/ms-information/symptoms/anxiety/

Ganz, P. A. (2002). Quality of life in long-term, disease-free survivors of breast cancer: A follow-up study. *Cancer Spectrum Knowledge Environment*, 94(1), 39–49. https://doi.org/10.1093/jnci/94.1.39

Garfield, A. C., & Lincoln, N. B. (2012). Factors affecting anxiety in multiple sclerosis. Disability and Rehabilitation, 34, 2047–2052.

https://doi.org//10.3109/09638288.2012.667503

- Gay, M.-C., Bungener, C., Thomas, S., Vrignaud, P., Thomas, P. W., Baker, R., Montel, S., Heinzlef, O., Papeix, C., Assouad, R., & Montreuil, M. (2017). Anxiety, emotional processing and depression in people with multiple sclerosis. *BMC Neurology*, *17*(43), 1–10. <u>https://doi.org/10.1186/s12883-017-0803-8</u>
- Gay, M.-C., Vrignaud, P., Garitte, C., & Meunier, C. (2010). Predictors of depression in multiple sclerosis patients. *Acta Neurologica Scandinavica*, 121(3), 161–170. https://doi.org/10.1111/j.1600-0404.2009.01232.x
- Ghezzi, A., & Zaffaroni, M. (2008). Female-specific issues in multiple sclerosis. *Expert Review* of Neurotherapeutics, 8(6), 969–977.doi:10.1586/14737175.8.6.969
- Glanz, K., Rimer, B., & Viswanath, K. (2008). *Health behavior and health education: Theory, research, and practice.* Jossey-Bass.
- Green, R., Kalina, J., Ford, R., Pandey, K., & Kister, I. (2016). SymptoMScreen: A tool for rapid assessment of symptom severity in MS across multiple domains. *Applied Neuropsychology: Adult, 24*(2), 183–189. https://doi.org/10.1080/23279095.2015.1125905
- Grimaldi, L. M. E., Palmeri, B., Salemi, G., Giglia, G., D'Amelio, M., Grimaldi, R., Vitello, G., Ragonese, P., & Savettieri, G. (2006). High prevalence and fast rising incidence of

multiple sclerosis in Caltanissetta, Sicily, Southern Italy. *Neuroepidemiology*, 28(1), 28–
32. https://doi.org/10.1159/000097853

Hanna, M., & Strober, L. B. (2020). Anxiety and depression in multiple sclerosis (MS):
 Antecedents, consequences, and differential impact on well-being and quality of life.
 Multiple Sclerosis and Related Disorders, 44.

https://doi.org/10.1016/j.msard.2020.102261

- Harbo, H. F., Gold, R., & Tintoré, M. (2013). Sex and gender issues in multiple sclerosis. Therapeutic Advances in Neurological Disorders, 6(4), 237–248. https://doi.org/10.1177/1756285613488434
- Hartoonian, N., Terrill, A. L., Beier, M. L., Turner, A. P., Day, M. A., & Alschuler, K. N.
 (2015). Predictors of anxiety in multiple sclerosis. *Rehabilitation Psychology*, 60(1), 91–98. <u>https://doi.org/10.1037/rep0000019</u>
- Helgeson, V. S., Cohen, S., Schulz, R., & Yasko, J. (2000). Group support interventions for women with breast cancer: Who benefits from what? *Health Psychology*, 19(2), 107–114. https://doi.org/10.1037/0278-6133.19.2.107
- Henry, A., Tourbah, A., Camus, G., Deschamps, R., Mailhan, L., Castex, C., ... Montreuil, M. (2019). Anxiety and depression in patients with multiple sclerosis: The mediating effects of perceived social support. *Multiple Sclerosis and Related Disorders*, 27, 46–51. https://doi.org/10.1016/j.msard.2018.09.039
- Honarmand, K., & Feinstein, A. (2009). Validation of the Hospital Anxiety and Depression Scale for use with multiple sclerosis patients. Multiple Sclerosis Journal, 15(12), 1518–1524. https://doi.org/10.1177/1352458509347150

- House J. S., Landis K. R., & Umberson, D. (1988). Social relationships and health. *Science*, 241(4865), 540–545. https://doi.org/10.1126/science.3399889
- Ibbotson, T., Maguire, P., Selby, P., Priestman, T., & Wallace, L. (1994). Screening for anxiety and depression in cancer patients the effects of disease and treatment. *European Journal of Cancer, 30*, 37–40.
- Jobin, C., Larochelle, C., Parpal, H., Coyle, P. K., & Duquette, P. (2010). Gender Issues in Multiple Sclerosis: An Update. *Women's Health, 6*(6), 797–820. doi:10.2217/whe.10.69
- Johnson, G., Burvill, P. W., Anderson, C. S., Jamrozik, K., Stewartwynne, E. G., Chakera, T. M. H. (1995). Screening instruments for depression and anxiety following stroke experience in the Perth Community Stroke Study. *Acta Psychiatrica Scandinavica*, *91*, 252–257.
- Jones, K. H., Ford, D. V., Jones, P. A., John, A., Middleton, R. M., Lockhart-Jones, H., . . . Noble, J. G. (2012). A large-scale study of anxiety and depression in people with multiple sclerosis: A survey via the web portal of the UK MS register. PLoS ONE, 7, e41910. https://doi.org/10.1371/journal.pone.0041910
- Kasser, S. L., & Kosma, M. (2018). Social cognitive factors, physical activity, and mobility impairment in adults with multiple sclerosis. *Behavioral Medicine (Washington, DC)*, 44(4), 306–313. https://doi.org/10.1080/08964289.2017.1368441

Kazdin, A. E. (2000). Encyclopedia of psychology. American Psychological Association.

Kirchner, T., & Lara, S. (2011). Stress and depression symptoms in patients with multiple sclerosis: The mediating role of the loss of social functioning. *Acta Neurologica Scandinavica*, 123(6), 407–413. https://doi.org/10.1111/j.1600-0404.2010.01422.x

- Korostil, M., & Feinstein, A. (2007). Anxiety disorders and their clinical correlates in multiple sclerosis patients. *Multiple Sclerosis (Houndmills, Basingstoke, England)*, *13*(1), 67–72.
- Kratz, A. L., Braley, T. J., Foxen-Craft, E., Scott, E., Murphy, J. F., III, & Murphy, S. L. (2017).
 How do pain, fatigue, depressive, and cognitive symptoms relate to well-being and social and physical functioning in the daily lives of individuals with multiple sclerosis? *Archives of Physical Medicine and Rehabilitation*, *98*, 2160–2166.
 https://doi.org/10.1016/j.apmr.2017.07.004
- Lincoln, N. B., Yuill, F., Holmes, J., Drummond, A. E., Constantinescu, C. S., Armstrong, S., et al. (2011). Evaluation of an adjustment group for people with multiple sclerosis and low mood: A randomized controlled trial. *Multiple Sclerosis*, 17(10), 1250–1257.
- Linden, W., & Vodermaier, A. (2012). Mismatch of desired versus perceived social support and associated levels of anxiety and depression in newly diagnosed cancer patients. *Supportive Care in Cancer*, 20(7), 1449–1456. <u>https://doi.org/10.1007/s00520-011-1228-</u><u>3</u>
- Linden, W., Vodermaier, A., McKenzie, R., & Duncan, G. (2012). Anxiety and depression after cancer diagnosis: Prevalence rates by cancer type, gender, and age. *Journal of Affective Disorders, 141*, 343–351.
- Linden, W., Andrea Vodermaier, A., McKenzie, R., Barroetavena, M. C., Yi, D., & Doll, R.
 (2009). The psychosocial screen for cancer (PSSCAN): further validation and normative data. *Health and quality of life outcomes*, *7*, 16. https://doi.org/10.1186/1477-7525-7-16
- Lorefice, L., Fenu, G., Trincas, G., Moro, M. F., Frau, J., Coghe, G. C., ... Carta, M. G.
 (2015). Progressive multiple sclerosis and mood disorders. *Neurological Sciences*, *36*(9), 1625–1631. https://doi.org/10.1007/s10072-015-2220-3

 Lotrich, F. E., El-Gabalawy, H., Guenther, L. C., & Ware, C. F. (2011). The role of inflammation in the pathophysiology of depression: Different treatments and their effects. *The Journal of Rheumatology Supplement, 88,* 48–54. https://doi.org/10.3899/jrheum.110903

- Manne, S. L., Taylor, K. L., Dougherty, J., & Kemeny, N. (1997). Supportive and negative responses in the partner relationship: Their association with psychological adjustment among individuals with cancer. *Journal of Behavioral Medicine*, 20, 101–125.
- Marrie, R.A., & Goldman M. (2007). Validity of performance scales for disability assessment in multiple sclerosis. *Multiple Sclerosis Journal*, 13(9),1176-1182.

doi:10.1177/1352458507078388

- Marrie, R. A., Fisk, J. D., Stadnyk, K. J., Tremlett, H., Wolfson, C., Warren, S., Bhan, V., & Yu,
 B. N. (2014). Performance of administrative case definitions for comorbidity in multiple sclerosis in Manitoba and Nova Scotia. *Chronic Diseases and Injuries in Canada, 34*, 145–153.
- Marrie, R. A., Fisk, J. D., Yu, B. N., Leung, S., Elliott, L., ... Patten, S. B. (2013). Mental comorbidity and multiple sclerosis: validating administrative data to support populationbased surveillance. *BMC Neurology*, *13*(1). https://doi.org/10.1186/1471-2377-13-16
- Marrie, R. A., Horwitz, R. I., Cutter, G., Tyry, T., & Vollmer, T. (2010). Association between comorbidity and clinical characteristics of MS. *Acta Neurologica Scandinavica*, 124(2), 135–141. https://doi.org/10.1111/j.1600-0404.2010.01436.x
- Marrie, R. A., Reingold, S., Cohen, J., Stuve, O., Trojano, M., Sorensen, P. S., Cutter, G., & Reider, N. (2015). The incidence and prevalence of psychiatric disorders in multiple

sclerosis: a systematic review. *Multiple Sclerosis*, *21*, 305–317. https://doi.org/<u>10.1177/1352458514564487</u>

- Matire, L. M., Stephens, M. A. P., Druley, J. A., & Wojno, W. C. (2002). Negative reactions to received spousal care: Predictors and consequences of miscarried support. *Health Psychology*, 21(2), 167–176. https://doi.org/10.1037/0278-6133.21.2.164
- Miclea, A., Salmen, A., Zoehner, G., Diem, L., Kamm, C. P., Chaloulos-Iakovidis, P., ...
 Hoepner, R. (2019). Age-dependent variation of female preponderance across different phenotypes of multiple sclerosis: A retrospective cross-sectional study. *CNS Neuroscience & Therapeutics*, *25*(4), 527. <u>https://doi.org/10.1111/cns.13083</u>
- Minihan, E., Gavin, B., Kelly, B. D., & McNicholas, F. (2020). COVID-19, mental health and psychological first aid. *Irish Journal of Psychological Medicine*, 37(4), 259–263. https://doi.org/10.1017/ipm.2020.41
- Mohr, D. C., Boudewyn, A. C., Goodkin, D. E., Bostrom, A., & Epstein, L. (2001). Comparative out-comes for individual cognitive-behavior therapy, supportive–expressive group psychotherapy, and sertraline for the treatment of depression in multiple sclerosis. *Journal of Consulting and Clinical Psychology*, 69, 942–949.
- Mohr, D. C., Cox, D., & Merluzzi, N. (2005). Self-injection anxiety training: A treatment for patients unable to self-inject injectable medications. *Multiple Sclerosis*, *11*(2), 182–185.

Mohr, D. C., Dick, L. P., Russo, D., Pinn, J., Boudewyn, A. C., Likosky, W., & Goodkin, D. E. (1999). The psychosocial impact of multiple sclerosis: Exploring the patient's perspective. *Health Psychology*, 18(4), 376–382. https://doi.org/10.1037/0278-<u>6133.18.4.376</u>

- Morrow, S. A., Drake, A., Zivadinov, R., Munschauer, F., Weinstock-Guttman, B., & Benedict, R. H. B. (2010). Predicting loss of employment over three years in multiple sclerosis:
 Clinically meaningful cognitive decline. *The Clinical Neuropsychologist, 24*, 1131–1145. https://doi.org/10.1080/13854046.2010.511272
- National Institute of Mental Health. (2017a). *Anxiety disorders*. Retrieved April 7, 2019, from <u>https://www.nimh.nih.gov/health/statistics/any-anxiety-disorder.shtml</u>
- National Institute of Mental Health. (2017b). *Major depression*. Retrieved April 7, 2019, from https://www.nimh.nih.gov/health/statistics/major-depression.shtml
- National MS Society. (2018). *Secondary progressive MS (SPMS)*. Retrieved August 26, 2019, from <u>https://www.nationalmssociety.org/What-is-MS/Types-of-MS/</u>
- Nordin, L., & Rorsman, I. (2012). Cognitive behavioral therapy in multiple sclerosis: A randomized controlled pilot study of acceptance and commitment therapy. *Journal of Rehabilitation Medicine*, *44*(1), 87–90.
- Oliveira, D. S., Mendonça, L. V. F., Sampaio, R. S. M., Castro-Lopes, J. M. P. D. de, & Azevedo, L. F. R. de. (2019). The impact of anxiety and depression on the outcomes of chronic low back pain multidisciplinary pain management—A multicenter prospective cohort study in pain clinics with one-year follow-up. *Pain Medicine*, 20(4), 736–746.
- Özdin, S., & Bayrak Özdin, Ş. (2020). Levels and predictors of anxiety, depression and health anxiety during COVID-19 pandemic in Turkish society: The importance of gender. *International Journal of Social Psychiatry*, 66(5), 504–511.

https://doi.org/10.1177/0020764020927051

Patten, S. B., Marrie, R. A., Carta, M. G. (2017). Depression in multiple sclerosis. *International Review of Psychiatry*, 29, 463–472. <u>https://doi.org/10.1080/09540261.2017.1322555</u>

Pompe, R. S., Krüger, A., Preisser, F., Karakiewicz, P. I., Michl, U., Graefen, M., ... Tilki, D. (2018). The impact of anxiety and depression on surgical and functional outcomes in patients who underwent radical prostatectomy. *European Urology Focus*. https://doi.org/10.1016/j.euf.2018.12.008

Qualtrics. (2018). Security statement. *Qualtrics*. Retrieved from https://www.qualtrics.com/security-statement/

- Reynolds, J. S., & Perrin, N. A. (2004). Mismatches in Social Support and Psychosocial Adjustment to Breast Cancer. *Health Psychology*, 23(4), 425–430. https://doi.org/10.1037/0278-6133.23.4.425
- Robb, C. E., de Jager, C. A., Ahmadi-Abhari, S., Giannakopoulou, P., Udeh-Momoh, C.,
 McKeand, J., Price, G., Car, J., Majeed, A., Ward, H., & Middleton, L. (2020).
 Associations of social isolation with anxiety and depression during the early COVID-19
 pandemic: A survey of older adults in London, UK. *Frontiers in Psychiatry*, *11*, 591120.
 https://doi.org/10.3389/fpsyt.2020.591120
- Rommer, P. S., Sühnel, A., König, N., & Zettl, U.-K. (2017). Coping with multiple sclerosis: The role of social support. *Acta Neurologica Scandinavica*, *136*(1), 11–16. <u>https://doi.org/10.1111/ane.12673</u>
- Roohafza, H. R., Afshar, H., Keshteli, A. H., Mohammadi, N., Feizi, A., Taslimi, M., & Adibi,
 P. (2014). What's the role of perceived social support and coping styles in depression and anxiety? *Journal of Research in Medical Sciences: The Official Journal of Isfahan* University of Medical Sciences, 19(10), 944–949.
- Rook, K. S. (1984). The negative side of social interaction: Impact on psychological well-being. Journal of Personality and Social Psychology, 46, 1097–1108.

- Rosiak, K., & Zagożdżon, P. (2018). Quality of life and social support in patients with multiple sclerosis. *Psychiatria Polska*, *52*(5), 923.
- Salari, N., Hosseinian-Far, A., Jalali, R. Vaisi-Raygani, A., Rasoulpoor, S., Mohammadi, M., Rasoulpoor, S., & Khaledi-Paveh, B. (2020). Prevalence of stress, anxiety, depression among the general population during the COVID-19 pandemic: A systematic review and meta-analysis. *Global Health*, 16(57). https://doi.org/10.1186/s12992-020-00589-w
- Samulowitz, A., Gremyr, I., Eriksson, E., & Hensing, G. (2018). "Brave men" and "emotional women": A theory-guided literature review on gender bias in health care and gendered norms towards patients with chronic pain. *Pain Research and Management*, 2018. https://doi.org/10.1155/2018/6358624
- Schapiro, R. T. (2014). Managing the symptoms of multiple sclerosis (6th ed). Demos Health.
- Simmons, R. D. (2010). Life issues in multiple sclerosis. *Nature Reviews Neurology*, *6*(11), 603–610. https://doi.org/10.1038/nrneurol.2010.143
- Stapleton, J. N., Mack, D. E., & Ginis, K. A. M. (2017). Social influence, physical activity, and social cognitions among adults with physical disability: A meta-analysis. *Kinesiology Review*, 6(3), 271–285. https://doi.org/10.1123/kr.2016-0002
- Stein, M., Roy-Byrne, P., Craske, M., Bystritsky, A., Sullivan, G., Pyne, J., . . . Sherbourne, C. (2005). Functional impact and health utility of anxiety disorders in primary care outpatients. *Medical Care, 43*(12), 1164–1170. https://doi.org/10.1097/01.mlr.0000185750.18119.fd
- Stenager, E., Knudsen, L., & Jensen, K. (1994) Multiple sclerosis: Correlation of anxiety, physical impairment and cognitive dysfunction. *Italian Journal of Neurology*, 15, 99– 103.

- Stern, B. Z., Strober, L., DeLuca, J., & Goverover, Y. (2018). Subjective well-being differs with age in multiple sclerosis: A brief report. *Rehabilitation Psychology*, 63(3), 474–478.
- Stokes, J. P., & Wilson, D. G. (1984). The inventory of socially supportive behaviors:
 Dimensionality, prediction, and gender differences. *American Journal of Community Psychology*, 12(1), 53–69. https://doi.org/10.1007/bf00896928
- Sutton, T. (2017) *Multiple sclerosis: Perspectives, clinical aspects and cognitive challenges.* Nova Science Publishers.
- Tan-Kristanto, S., & Kiropoulos, L. A. (2015). Resilience, self-efficacy, coping styles and depressive and anxiety symptoms in those newly diagnosed with multiple sclerosis.
 Psychology, Health & Medicine, 20(6), 635–645.
 https://doi.org/10.1080/13548506.2014.999810
- Tough, H., Siegrist, J., & Fekete, C. (2017). Social relationships, mental health and wellbeing in physical disability: A systematic review. *BMC Public Health*, 17, 414. <u>https://doi.org/10.1186/s12889-017-4308-6</u>
- Uccelli, M. M., Mohr, L. M., Battaglia, M. A., Zagami, P., & Mohr, D. C. (2004). Peer support groups in multiple sclerosis: Current effectiveness and future directions. Multiple Sclerosis Journal, 10(1), 80–84. https://doi.org/10.1191/1352458504ms9730a
- United States Department of Veteran Affairs. (2018). *Multiple sclerosis centers of excellence*. Retrieved April 13, 2019, from

https://www.va.gov/MS/Professionals/diagnosis/Determination_of_MS_Subtypes.asp

Varma, P., Junge, M., Meaklim, H., & Jackson, M.L. (2021). Younger people are more vulnerable to stress, anxiety and depression during COVID-19 pandemic: A global crosssectional survey. *Progress in Neuro-Psychopharmacology and Biological Psychiatry*, 109(13). <u>https://doi.org/10.1016/j.pnpbp.2020.110236</u>

- Wakefield, J. R. H., Bickley, S., & Sani, F. (2013). The effects of identification with a support group on the mental health of people with multiple sclerosis. *Journal of Psychosomatic Research*, 74(5), 420–426. <u>https://doi.org/10.1016/j.jpsychores.2013.02.002</u>
- Wood, B., van der Mei, I. A. F., Ponsonby, A. L., Pittas, F., Quinn, S., Dwyer, T., . . . Taylor, B.
 V. (2013). Prevalence and concurrence of anxiety, depression and fatigue over time in multiple sclerosis. *Multiple Sclerosis Journal*, *19*, 217–224.
 https://doi.org/10.1177/1352458512450351
- Zigmond, A. S., & Snaith, R. P. (1983). *The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavica*, 67(6), 361–370. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x
- Zorzon, M., de Masi, R., Nasuelli, D., Ukmar, M., Pozzi Mucelli, R., Cazzato, G., Bratina, A., & Zivadinov, R. (2001). Depression and anxiety in multiple sclerosis. A clinical and MRI study in 95 subjects. *Journal of Neurology*, 248(5), 416 –

421. https://doi.org/10.1007/s004150170184

APPENDIX A

Dear Potential Volunteer:

Purpose of Research

I am conducting this study as a student in the Counseling Psychology PhD program in the Department of Professional Psychology and Family Therapy at Seton Hall University. The purpose of this study is to explore the effects of social support on anxious and depressive symptoms in women who have been diagnosed with Multiple Sclerosis (MS).

Procedures and Voluntary Participation

Participation is completely voluntary. If you choose to participate you may withdraw from this study at any time without any consequence. Your consent will be implied by your choosing to complete the study via the survey link at the end of this letter. Participation in this study involves completing a demographic (background) questionnaire and 4 brief surveys. Total participation time will take approximately 15 – 20 minutes.

Anonymity Preservation and Confidentiality

This study will be conducted through anonymous surveys. Your name will not be used in connection with the study and that responses will not be linked to your identity. The surveys are accessed through a secure link connected to a system called Qualtrics. Survey respondents will remain anonymous; no information that could personally identify you will be requested. Information and data received from the Qualtrics system will be stored on a USB memory key, which will be kept in a locked, secure location.

Anticipated Risks and Discomfort

There are minimal foreseen risks or discomfort involved in this survey study. Risks are minimized by the use of brief surveys and through the inclusion of positive strength-based questionnaires. You are free to withdraw from the study at any time without penalty. If you experience significant distress, you are urged to discuss those feelings with a mental health professional at the National Crisis Hotline at 1-800-273-8255 or by using the American Psychological Association's psychologist locator service at: https://locator.apa.org/? ga=2.39652515.1684085803.1519678909-1000026211.1494004804

Benefits to Research

Participation in this study may provide valuable information in educating healthcare providers, caregivers, and loved ones of individuals with MS. It also may assist in reducing anxious and depressive symptoms in this population.

Contact Information

If there are any questions regarding this study or what is expected of your voluntary participation in this study, please contact me at the email address below. You may also contact my advisor, Dr. Pamela Foley, at 973-275-2742 or pamela.foley@shu.edu.

Specific questions regarding the research or research subject's rights should be directed to the Director of the Institutional Review Board at Seton Hall University, Dr. Michael LaFountaine, at (973) 313-6314.

Sincerely,

Elena Thomopoulos, MSEd Counseling Psychology Doctoral Student Department of Professional Psychology and Family Therapy Seton Hall University <u>Elena.thomopoulos@student.shu.edu</u>

Survey Link:

Age:	APPENDIX B				
What subtype of Multiple Sclerosis do you have?	RRMS	PPMS	Other		
At what age were you diagnosed with Multiple Sc	lerosis?				
Are you currently under the care of a neurologist?	Yes No				
Race/Ethnicity (check all that apply): White					
Hispanic or Latinx					
Black or African American					
Native American or American Indian					
Asian/Pacific Islander					
Other					
Relationship Status:					
Single					
Married/Partnered					
Divorced					
Widowed					
In a Relationship					
Employment Status (Check all that apply):					
Working Full-Time (40+ hours a week)					
Working Part-Time (less than 40 hours a week)					
Student					
Unemployed					
On disability					
On medical leave					

What state do you live in? _____

APPENDIX C



Elena A Thomopoulos Wed 7/24/2019 3:05 PM Manuel.Barrera@asu.edu ⊗



Hello Dr. Barrera,

I hope this email finds you well.

My name is Elena Thomopoulos and I am currently a fourth-year doctoral student in counseling psychology at Seton Hall University in New Jersey.

I am writing to you to ask for permission to use your scale the Inventory of Socially Supportive Behaviors (ISSB). Currently, I am in the process of writing up my dissertation proposal and the topic would be best explored with the use of your measure. I have worked with patients with MS for over a year and would like to look at mismatches in social support and how it may affect anxious and depressive symptoms in women with MS. I came across a study entitled "Mismatches in Social Support and Psychosocial Adjustment in Breast Cancer" by Dr. Julie Reynolds and Dr. Nancy Perrin. I noticed that they utilized your measure, but used different scoring than initially intended. I hope to use their method of scoring in order to find the "mismatch" aspect of my study.

With this in mind, I would like to ask your permission to use your scale, as well as utilize the scoring used in this previous study.

I appreciate your time and hope to hear from you soon.

All the best,

Elena



Manuel Barrera <atmxb@asu.edu> Wed 7/24, 5:53 PM

Elena--

I grant you permission to use the ISSB in research that has been approved by your IRB. I am not familiar with the scoring procedure you described, but you may revise the ISSB to fit the purposes of your research.

BTW--I have been living with progressive MS for 40 years.

Dr. Barrera



APPENDIX D

	0 – not affected at all	1 – very mild limitation/ I make minor adjustments	2 – mild limitation/ I make frequent adjustments	3 – moderate limitation/l reduced my daily activities	4 – severe limitation/I gave up some activities	5- very severe limitation/l'm unable to do many daily activities	6 – total limitation/ I'm unable to do most daily activities
Walking/Mobility	0	1	2	3	4	5	6
Hand function/Dexterity Hand coordination, hand tremors	0	1	2	3	4	5	6
Spasticity & Stiffness Muscle cramping or muscle tightness	0	1	2	3	4	5	6
Bodily Pain Achiness, tenderness	0	1	2	3	4	5	6
Sensory symptoms Numbness, tingling, or burning	0	1	2	3	4	5	6
Bladder control Urinary urgency, frequency, hesitancy	0	1	2	3	4	5	6
Fatigue	0	1	2	3	4	5	6
Vision Blurry vision, double vision	0	1	2	3	4	5	6
Dizziness Feeling off balance, 'spinning'/vertigo	0	1	2	3	4	5	6
Cognitive function Memory, concentration problems	0	1	2	3	4	5	6
Depression Depressed thoughts, low mood	0	1	2	3	4	5	6
Anxiety Feelings of stress; panic attacks	0	1	2	3	4	5	6

APPENDIX E



June 5, 2020

Elena Thomopoulos Seton Hall University

Re: Study ID# 2020-089

Dear Ms. Thomopoulos,

The Research Ethics Committee of the Seton Hall University Institutional Review Board reviewed and approved your research proposal entitled "The Effects of Matched and Mismatched Social Support on Anxious and Depressive Symptoms in Women with Multiple Sclerosis" as resubmitted. This memo serves as official notice of the aforementioned study's approval as exempt. Enclosed for your records are the stamped original Consent Form and recruitment flyer. You can make copies of these forms for your use.

The Institutional Review Board approval of your research is valid for a one-year period from the date of this letter. During this time, any changes to the research protocol, informed consent form or study team must be reviewed and approved by the IRB prior to their implementation.

You will receive a communication from the Institutional Review Board at least 1 month prior to your expiration date requesting that you submit an Annual Progress Report to keep the study active, or a Final Review of Human Subjects Research form to close the study. In all future correspondence with the Institutional Review Board, please reference the ID# listed above.

Thank you for your cooperation.

Sincerely,

MARA PHANEY Mara C. Podvey, PhD, OTR Associate Professor Co-Chair, Institutional Review Board

Office of the Institutional Review Board Presidents Hall · 400 South Orange Avenue · South Orange, New Jersey 07079 · Tel: 973.275.4654 · Fax 973.275.2978 · www.shu.ødu

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