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Multiple Sclerosis (MS) is a chronic degenerative autoimmune disease of the central nervous system that affects approximately 2.1 million people world-wide (National Multiple Sclerosis Society, 2005). Symptoms include limitations with both physical (coordination, muscle weakness, vision problems, etc.) and cognitive functioning and vary by individual. There is currently no cure for MS and treatment is based around symptom management (Coyle & Hamaad, 2006). One means for symptom management is physical activity (PA). PA has been shown to effectively aid symptom management by reducing the number, length, and duration of disease flare-ups (Motl, McAuley, & Snook, 2005), as well as increasing overall quality of life (Stuifbergen, Blozis, Harrison, & Becker, 2006). In spite of this evidence, the MS population is one of the most inactive segments of the population, even among patients with chronic diseases (Motl & Snook, 2008). Understanding what motivates this population to be physically active is the first step in developing an effective, sustainable, PA intervention for disease management. Using Path Analysis, this study examined potential predictors of motivation for PA in individuals with MS ( $n = 215$ ) finding self-determined motivation, in conjunction with self-efficacy, as predictors of PA participation, and self-efficacy and PA participation as a predictors of quality of life. In the model, self-efficacy and identified regulation predicted PA participation, and PA participation predicted quality of life,  $\chi^2(1) = .02$ ,  $p = .867$ ; RMSEA = .00; CFI = 1.0; SRMR = .002. Open-ended responses from participants supported the model, indicating that self-efficacy and identified regulation

were predictors of PA, and PA was a predictor of increased overall quality of life. The findings and resulting model may be used to guide future interventions to promote PA participation in individuals with MS and consequently enhance long-term quality of life.

AN EXPLORATION INTO THE MOTIVATION FOR PHYSICAL ACTIVITY  
IN INDIVIDUALS WITH MULTIPLE SCLEROSIS

by

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Approved by

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Committee Chair

To Grace. Thank you for showing me how to keep my eye on the prize.

APPROVAL PAGE

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## CHAPTER I

### INTRODUCTION

Multiple Sclerosis (MS) affects approximately 2.1 million otherwise-healthy people world-wide. It is a chronic degenerative autoimmune disease of the central nervous system for which there is no known cure and the only course of action is disease management in the form of slowing progression and controlling symptoms (National Multiple Sclerosis Society, 2005). Individuals are usually diagnosed in their late teens to early 20's and rarely have a reduced life expectancy, making it a disease that people live with for a lifetime (Iezzoni, 2010). Symptoms of MS can include (but are not limited to) muscle weakness, loss of coordination, cognitive impairments, vision problems, bowel and bladder control problems, and anything else that is neurologically based, meaning the list of symptoms is extremely vast and varies by individual (Coyle & Hamaad, 2006). These symptoms can drastically reduce quality of life for the patient. In order to increase overall quality of life long-term for the individual, it becomes imperative that all possible steps are taken to slow disease progression and control symptoms. Methods for disease management primarily include drug therapy, however increasingly, patients are turning to other lifestyle modifications to aid in overall disease control. One of these modifications that has been extremely successful is the incorporation of regular physical activity.

Physical activity (PA) has been shown to be an effective means to aid in MS symptom management for many patients (Motl, McAuley, & Snook, 2005; Motl &

Pilutti, 2012). This symptom management is seen in physical and cognitive symptoms, and appears to aid in the reduction of the length and duration of disease flare-ups (Snook & Motl, 2009; Stuifbergen et al., 2006). For this reason, PA appears to be a viable intervention for many individuals with MS to aid in long-term disease management. Integrating PA into the lives of people upon initial diagnosis (if they are not already active), before symptoms progress to a point where PA is physically impossible, seems to be a way to aid in disease management with a simple lifestyle change. Recent recommended activity levels for individuals with MS to see benefits are relatively low and should be achievable for most individuals (Latimer-Cheung et al., 2013). In spite of this growing body of evidence, the MS population as a whole is very inactive (Motl & Snook, 2008; Petajan et al., 1996). This presents a complex problem; one of the very things that could aid in symptom control is often absent from the lives of these individuals.

In addition to the physical benefits that MS patients see from PA participation, there also appear to be benefits to overall quality of life (Motl & Snook, 2008; Motl & Gosney, 2008; Petajan et al., 1996; Stuifbergen et al., 2006; Sutherland, Andersen, & Stoové, 2001). This makes sense in light of what disease symptom control can represent to an individual. Controlling or slowing the progression of the aforementioned symptoms, even if just partially, could have a huge impact on how patients experience their lives. For instance, controlling symptoms a small amount could mean the difference between being sedentary and being mobile enough to get around one's home unaided, walk up and down stairs, or be able to drive a car. These enhanced abilities translate into improved

quality of life. For this reason, there is a direct link between symptoms and reported quality of life (Motl & Gosney, 2008).

Previous research on motives for PA in individuals with MS has followed Social Cognitive Theory (SCT) (Motl & Snook, 2008; Young, Plotnikoff, Collins, Callister, & Morgan, 2014). Briefly, SCT is a cognitive behavioral theory based on the individual's self-efficacy for behavior and their outcome expectancies for those behaviors. It focuses on the relationship between the person, their behavior, and the environment, and it states that behavior is a result of the combination of the integrative influences of the environment, experiences, and expected results (Bandura, 2004). SCT relies heavily on the concept of self-efficacy, and one's belief in the ability to accomplish a behavior, as the underlying explanation for behavior. The more self-efficacy an individual exhibits for a behavior, the more likely the individual is going to develop the behavior into a long-term activity.

The current project uses Self-Determination Theory (SDT), as well as self-efficacy, to examine the motivational aspects of PA participation in individuals with MS. Similar to SCT, SDT is based in the general cognitive behavioral framework. SDT relies on the basic needs of competency, autonomy, and relatedness as the driving constructs for behavior motivation and focuses on the origination of needs in the individual (Deci & Ryan, 1985, 2004). According to SDT, the more autonomously controlled the motivation is for a behavior, the more internalized the behavior becomes, and the more likely the behavior will continue. This resulting concept is self-determination (Deci & Flaste, 1996). Unlike SCT, which relies on quantity of motivation to predict behavior (amount of

self-efficacy), SDT also examines the origination of the motivation (the internalization of behavior as self-determination). In this way, SDT provides a framework that examines motivation in a detailed manner in order to predict participation.

There is support for using SDT and SCT in tandem to gain a better understanding of PA motivation. Self-efficacy has been shown to be related to the construct of perceived competence in SDT (Sweet, Fortier, Strachan, & Blanchard, 2012). By using self-efficacy to indicate the amount of motivation for PA, and SDT to indicate how self-determined the motivation is, a more complete picture of PA motivation emerges (Sweet et al., 2012). When specifically considering the MS population, the combination of self-efficacy and SDT may provide a clearer roadmap to increased PA participation, and consequently increased overall quality of life, as has been seen in other populations (Sweet et al., 2012). This deeper understanding of motivation is the goal of this project in order to eventually integrate this knowledge into future PA protocols for people with MS.

Additional evidence supporting the use of SDT and SCT comes from a 2014 case study examined a single individual with MS who was highly physically active as a competitive elite amateur mountain bike racer (Fasczewski, Gill, & Barrett, 2015). The results of the case study suggested that the motives for PA were linked to the participant's perceived ability to control her disease and that PA participation increased her overall quality of life. The participant reported living what she perceived to be a normal, healthy, active life, which she attributed to her continued PA participation. The underlying themes supported the theoretical approach of SDT and self-efficacy. This participant did struggle with many of the same issues seen in most MS patients (physical

challenges, depression) but she spoke of using these challenges as personal motivators to remain active. This research gives insight into one person with MS's perspective and approach to PA participation.

Following the aforementioned case study, the next logical step in this examination of motivational factors for PA participation was to expand to a group of highly physically active individuals with MS. Using SDT as a framework, pilot data were collected via surveys from 15 highly active individuals with MS. Additionally, semi-structured interviews were performed with 9 of these participants in order to add depth and context to the results of the survey data. The interviews focused on a) motivation and strategies used to maintain PA, and b) the benefits and impact of PA in their lives. Results indicated that participants were highly motivated, and the main themes were in line with SDT; participants described feelings of accomplishment and competence in both their PA and daily life, as well as a sense of independence and autonomy. Similarly, all participants cited benefits from PA that included enhanced satisfaction with life and an overall positive outlook on life. These results support the development of the current project that seeks to look at PA motivation and quality of life outcomes in the larger MS population.

The current study examines motivation for PA in individuals with MS using self-determined motivation, as defined by SDT, in conjunction with self-efficacy as predictors of PA participation. This project also examines the relationship between PA participation and quality of life. The goal of this investigation is to develop a model that can be used to understand and guide interventions to promote PA participation in individuals with MS and consequently enhance long-term quality of life. Before any effective PA intervention

protocol for the MS population can be designed using SDT (or any other theory) it is imperative that we understand the motivation for, and benefits of, PA in this population. This research takes a modeling approach with the aim of clarifying those relationships.

### **Purpose**

The aim of this research is to model the relationships among self-determined motivation, PA, and quality of life in individuals with MS. The overall proposed model (depicted in Figure 1) combines the two main research questions. The first part of the model, and research question 1, focus on the relationship of self-determined motivation and self-efficacy to PA. The second part of the model, and research question 2, focus on the relationship of physical activity to quality of life. Based on the existing literature with other populations, self-determined motivation impacts PA participation and PA predicts quality of life. A third research question will explore the question of model equivalency when it is divided by physical disability level to see if the model holds across disability level of the individual.



*Figure 1. Proposed Overall Model of the Relationship Between Self-Determined Motivation, PA, and Quality Of Life.*

## **Research Question 1**

**Are self-determined motivation and self-efficacy for PA related to PA levels in people with MS?** In accordance with SDT, individuals who are highly self-determined for a behavior exhibit high levels of the behavior (Deci & Ryan, 2004). Although SDT is the primary motivational framework for this research, self-efficacy will also be used as a predictor for PA. Past research with the MS population using SCT has suggested that self-efficacy is a key predictor of PA participation. Self-efficacy is related to the concept of perceived competence in SDT but remains a unique construct, lending support for a combined SDT/self-efficacy model (Sweet et al., 2012). Consequently, adding self-efficacy to self-determined motivation in this model may provide a more complete picture of motivation for PA.

***Hypothesis 1a:*** Self-determined motivation for PA is linearly related to PA participation in individuals with MS.

***Hypothesis 1b:*** Self-efficacy for PA is linearly related to PA participation in individuals with MS.

## **Research Question 2**

**Is PA participation related to quality of life?** It is expected that individuals with MS who are more physically active have higher perceived quality of life. In this research, quality of life is examined as overall life satisfaction (Diener, Emmons, Larsen, & Griffin, 1985) and also as a multi-dimensional construct including social, spiritual, emotional, cognitive, physical, and functional/activities of daily living (ADL), as well as integrated quality of life (Gill et al., 2011). It is expected that PA participation will be

related to overall life satisfaction and integrated quality of life; PA is also expected to relate to several dimensions of quality of life, with its strongest relationships to physical, functional (ADL), and emotional quality of life.

***Hypothesis 2a:*** PA participation is positively related to life satisfaction and integrated quality of life.

***Hypothesis 2b:*** PA participation is positively related to the individual quality of life dimensions (physical, functional/ADL), emotional, social, spiritual, cognitive).

Once research questions 1 and 2 were answered, they were combined to examine the relationships as a complete model. This model gives an accurate picture of the relationship between self-efficacy for PA, self-determined motivation for PA, PA participation, and quality of life. This overall model was used for research question 3.

### **Research Question 3**

**Does disease step (level of disability) change the relationships among motivation, PA, and quality of life?** This exploratory question has two parts. First, *is disability level related to PA participation, motivation or quality of life?* Second, *does the overall model of motivation, PA participation, and quality of life hold constant for different disability levels; that is, are the models of the relationships equivalent across disability level groups?* Previous research has found that the more disabled the individual is, the less likely it is that they participate in PA (Beckerman, de Groot, Scholten, Kempen, & Lankhorst, 2010). For this reason, disability level needs to be considered when examining motives for PA participation. Disability level will be assessed using the

Patient Determined Disease Step (PDDS) measure which gives a single score that determines the level of disease symptoms the patients is living with.

*Hypothesis 3a:* Disability/higher disease step will be linearly related to self-determined motivation for PA and PA participation.

*Exploratory research question:* Does the motivation/PA/QoL model hold across disability levels?

### **Proposed Model**

In combination, the first two research questions create the overall proposed model shown in figure 1. This model should lend insight into the level of self-determined motivation for PA individuals with MS exhibit, the role that self-efficacy plays in this relationship, as well as the overall impact that PA has on quality of life/satisfaction with life for this population. The third research question will then add understanding to the PA behavior of the MS population as related to disability status by examining this model across different disability levels. Gaining an understanding of the relationships in this model will allow future development of PA interventions that are rooted in a strong theoretical base.

## CHAPTER II

### LITERATURE REVIEW

This chapter will briefly examine the foundational literature used as rationale for this project. It begins with an examination of the basic physiology of MS, including treatment options, PA recommendations, and impact of PA on overall disease progression. There is then a discussion on current findings on the relationship between PA and quality of life in MS patients. Following that is an examination of the theories of behavior change relevant to this project, specifically focusing on Social Cognitive Theory, which has been used in previous research examining PA in MS patients; and Self-Determination Theory, which is the theoretical background for the current research.

#### **What is MS?**

Multiple Sclerosis is a chronic degenerative neurological disease that attacks the central nervous system (CNS) (National Multiple Sclerosis Society, 2005). It progresses at varying rates depending on the individual and type of MS. Once symptoms appear there is always progression. MS can affect any area of the nervous system; for this reason symptoms are variable and are not exhibited in exactly the same way for any two individuals (Coyle & Hamaad, 2006; Iezzoni, 2010). Because of these variations among patients, MS is a very complicated disease to diagnose and treat. Treatment usually involves multiple methods, which can include both drug therapies and more recently, PA. Current estimates put the number of people in the United States living with MS at

between 250,000 and 400,000 and there is no known cure (Iezzoni, 2010; “What is MS?,2012). MS is typically diagnosed when patients are in their late teens to late 20s, although it can be diagnosed in patients as late as 60 years old (Coyle & Hamaad, 2006). Most patients are otherwise healthy.

### **Basic Physiology of MS**

**The role of the Central Nervous System.** Understanding MS begins with a basic understanding of the Central Nervous System (CNS), its functions, and how MS limits these functions as the disease progresses (Iezzoni, 2010). The CNS is comprised of the brain and spinal cord and is the command center for all movement in the body, both voluntary (e.g. conscious muscle movement) and involuntary (e.g., unconscious organ functions), as well as all brain activity (e.g., learning, language, thought) (Talley, 2008). The job of the CNS is rapid communication and this is done using electrical and chemical signals. Cells within the CNS take two forms, nerve cells (neurons) and glia cells (neuroglia) (Brodal, 2010). Neurons are specialized cells that conduct and receive signals that dictate movement through the body. Neuroglia are supportive cells that exist in various forms and aid in the transmission of signals as well assess damage and perform reparative functions through the nervous system (Brodal, 2010). Communication in the nervous system originates in the brain and signals are sent from one neuron to the next until they arrive at the end location.

Neurons are comprised of a cell body and cytoplasm with two different types of extensions, dendrites and axons (Brodal, 2010). Most CNS neurons have several dendrites, which are short and branching and receive signals from other neurons. Some

neurons have dendrites that both send and receive signals (Brodal, 2010). Neurons with axons have only one axon and its purpose is to transmit signals (Brodal, 2010; Iezzoni, 2010). Axons vary in length depending on the type and location of the muscle that they are signaling. Axons terminate at a synapse where a signal is transmitted to the receiving cell telling it what action to execute or to inhibit (Brodal, 2010). The signal is transmitted using an electrical gradient which passes it along the outer membrane of the axon. To enhance the speed of transmission, a specific type of neuroglia called oligodendrocytes form a covering over the axon, which is called the myelin (Brodal, 2010; Iezzoni, 2010). Numerous oligodendrocytes attach to each axon with small gaps in between each oligodendrocyte, and this myelin increases the speed of the signal transmission (figure 2) (Iezzoni, 2010). The entire process of signal transmission appears almost instantaneous.

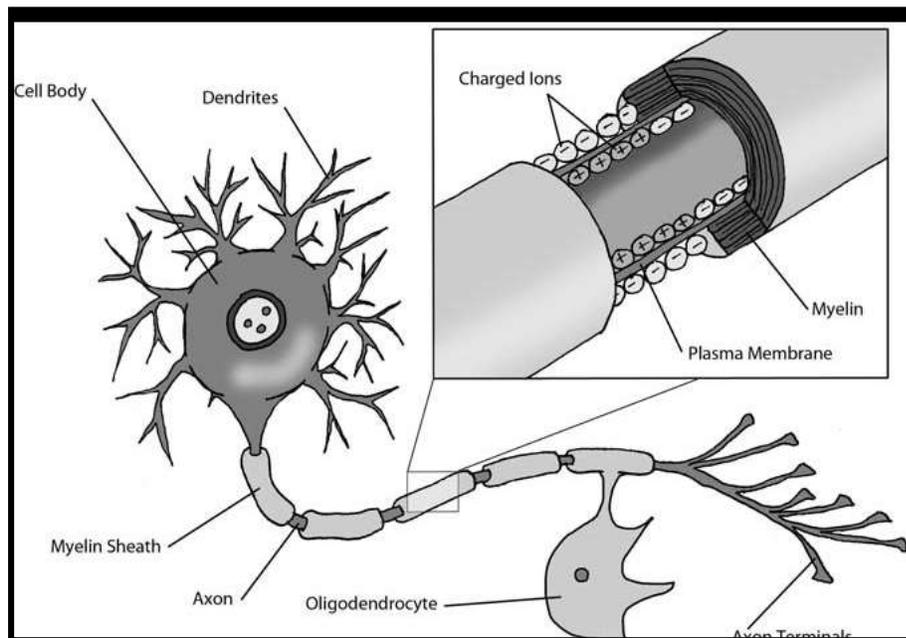
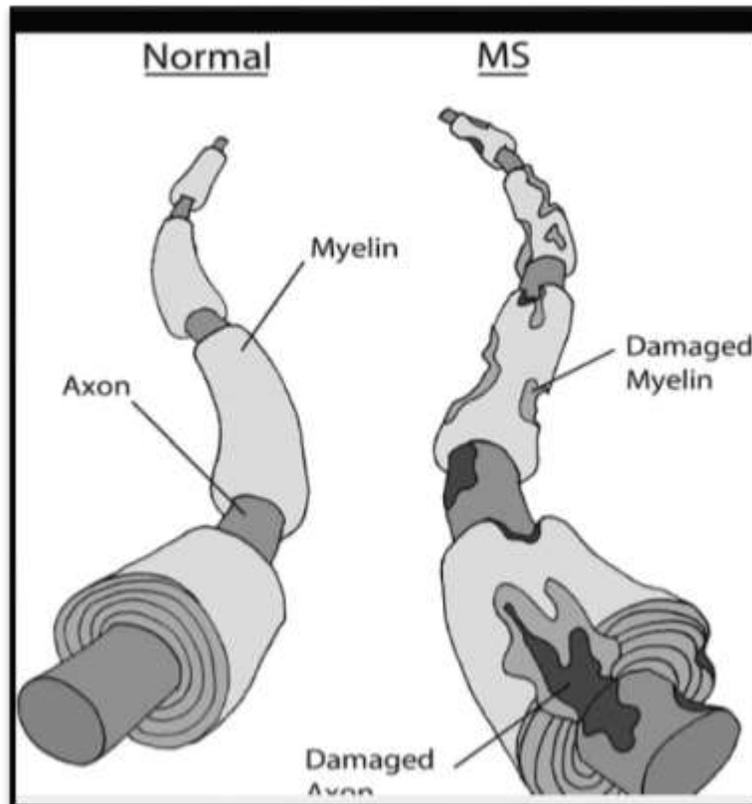


Figure 2. Basic Anatomy of a Neuron (Iezzoni, 2010).

MS is an inflammatory disease that is characterized by damage to the myelin covering, and consequently the underlying nerve cell fibers, leading to slowed or blocked transmission of signals (figure 3). This demyelination of the CNS results in limited functioning both physically and cognitively (Ji & Goverman, 2008; National Library of Medicine (U.S.), 2000). The reasons for this damage are still under debate, but most MS researchers believe that MS is an autoimmune disorder, meaning that the immune system malfunctions and attacks cells within the body instead of the foreign cells it is supposed to attack (Kaldor, 2013). The damage to the myelin and axon causes the transmission of the signal to be slowed; the most common symptoms include the loss of coordination, reduced cognitive ability, loss of muscle control, tingling sensation, loss of sensation, loss of sight as well as numerous other neurologic impairments (Boggs, 2008). The neuroglia that are specific to the repair of neurons attempt to fix this damage and the result is scar tissue (called lesions) that allow the neuron to continue functioning but at a reduced capacity (Boggs, 2008). Most commonly, individuals with MS have periods of symptom flare-up when this damage is occurring and then periods of more normal functioning, where the resulting scar tissue has formed and normal functioning has returned, albeit somewhat limited (Halper & Holland, 1996). Over time these lesions become more numerous and physical and cognitive functioning is increasingly reduced (Kalb, 1996; Kaldor, 2013). The lesions are what is seen in Magnetic Resonance Imaging (MRI) when an individual is initially diagnosed with MS and also what is examined when disease progression is measured (Fleming, 2002; Iezzoni, 2010). Depending on where these lesions are in the brain or spinal cord will determine the symptoms that a patient exhibits.

No two lesions are the same and no two individuals have the same number or type of lesions, which is why MS presents differently in each individual (Boggs, 2008; Fleming, 2002; Iezzoni, 2010). Lesions are typically found on the white matter in the nervous system, often near blood vessels (American College of Sports Medicine, 2002; Kaldor, 2013). The reason for this is not understood, but it is the basis for some of the newer experimental MS treatments that focus more on blood vessel involvement and less on neurological damage (Kaldor, 2013). So far the results from this research is mixed and the treatments are not considered an effective means of treatment (Kaldor, 2013).



*Figure 3. An Illustration of a Normal Neuron with Healthy Functioning Myelin and a Neuron with Damaged Myelin from MS (Iezzoni, 2010).*

**Diagnosis of MS.** Diagnosis of MS can be as varied as the disease itself. It may be challenging to diagnose because the disease presents differently in each case and many symptoms mimic other diseases. It is not uncommon for a patient to be diagnosed initially with a different neurological condition prior to the MS diagnosis (Kalb, 1996). In other cases of MS, the patient exhibits immediately with all the symptoms and it is very easy to quickly and accurately diagnose MS (Fleming, 2002). The current generally recognized protocol for diagnosis requires the patient to exhibit two or more white-matter lesions, two or more recognizable neurologic symptoms (or two or more exacerbations [flare-ups] that exhibited these symptoms – neurologic symptoms may not be evident between flare-ups) and an increase of Immunoglobulin G (which is the main antibody the immune system uses to control infection in body tissues) in the spinal fluid (American College of Sports Medicine, 2002). Typically a concrete diagnosis requires both an MRI to detect lesions and a lumbar puncture for the collection of spinal fluid. The type of MS the patient is initially diagnosed with is determined by the number, location and type of lesions, symptoms exhibited, and the existence of exacerbations and remissions (Fleming, 2002). The form of the disease may change over the lifetime of the patient and diagnosis is a dynamic and ongoing process (Fleming, 2002; Halper & Holland, 1996; Kalb, 1996).

**Types of MS.** MS is unpredictable in its progression and can take a number of different forms (Pakenham, 2006). The symptoms of MS can range from abnormal sensation (tingling, numbness), vision problems, fatigue, muscle weakness (more often in lower extremities because lesions tend to occur low on the spinal cord), motor skill problems, coordination, ataxia (speech problems), bladder and bowel problems, heat

sensitivity, chronic pain, vertigo and hearing problems, sexual dysfunction, and cognitive problems (Fleming, 2002; Kalb, 1996; National Library of Medicine, U.S., 2000; Sheet, 2006). As previously discussed, symptoms depend on the location and severity of the lesions and for this reason no two cases of MS are exactly the same. In spite of the drastic differences in MS symptoms from patient to patient, there are four different generally agreed upon classifications of the disease.

The most common form of MS is relapsing-remitting MS (RRMS), which is characterized by flare-ups where the patient experiences symptoms such as loss of coordination and cognitive functioning, fatigue, numbness, and weakness, followed by relapses in which the level of functioning returns to near normal (figure 4) (Fleming, 2002; Iezzoni, 2010). The flare-ups are called exacerbations (Iezzoni, 2010). These relapses tend to shorten, and normal functioning levels decrease as the disease progresses. Approximately 85% of patients diagnosed with MS initially present with RRMS and of these, 2 out of 3 are women (Coyle & Hamaad, 2006; Fleming, 2002; Iezzoni, 2010; Kalb, 1996). Particularly in RRMS, the stochastic nature of symptoms can make the initial MS diagnosis difficult (Fleming, 2002; Iezzoni, 2010). Individuals have vague symptoms that come and go (these are flare-ups where the myelin and axon are being damaged and then consequently repaired) and the symptoms are not consistent between patients. MS symptoms such as blurred vision, fatigue, weakness, and numbness can be attributed to many different diseases so when the patient does see a doctor, if an MRI is not ordered for diagnosis, it is not always clear what the underlying cause is (Kalb, 1996). It is not uncommon for an individual to live for years with mild RRMS before

being diagnosed. Often, symptoms are minor and sporadic so the patient does not seek medical advice until the disease has progressed to a point where it is obvious that there is a problem (Iezzoni, 2010).

Most cases of MS start as RRMS but eventually the disease evolves into secondary-progressive MS (SPMS) (Coyle & Hamaad, 2006; National Library of Medicine, U.S., 2000). SPMS is characterized by steady decline in functioning with possible short relapses between flare-ups. As depicted in figure 4, SPMS begins as RRMS and then at some point transitions to a more steady decline similar to other forms of the disease. Not all cases of RRMS develop into SPMS, and the timeline may be many years before this change occurs, but over time this evolution occurs in a majority of patients (Fleming, 2002).

A more aggressive form of MS is progressive-relapsing MS (PRMS). In this form, MS is characterized by constant progression of symptoms from the onset of disease with few relapses (figure 4) (Iezzoni, 2010). The relapses that are seen are brief and do not take the functional level of the patient back to normal levels. This type of MS only affects about 5% of cases. Patients with PRMS are typically diagnosed later in life (after the age of 40) and, unlike other forms of the disease, are equally distributed between genders (Coyle & Hamaad, 2006).

Finally, primary-progressive MS (PPMS) is characterized by steady worsening of symptoms from onset with no relapses (“What is MS?,” 2012). Patients with this type of MS make up about 10% of cases and have the worst prognosis for treatment and disease control. As seen in figure 4, once symptoms begin there is no reprieve, and decline of

functioning is at a steady rate. Lesions in PRMS are located on both the spinal cord and in the brain and are numerous from the onset (Fleming, 2002). Patients with either PPMS or PRMS have very little luck with the drug therapies that are used to control MS progression (Wagstaff, 2000).

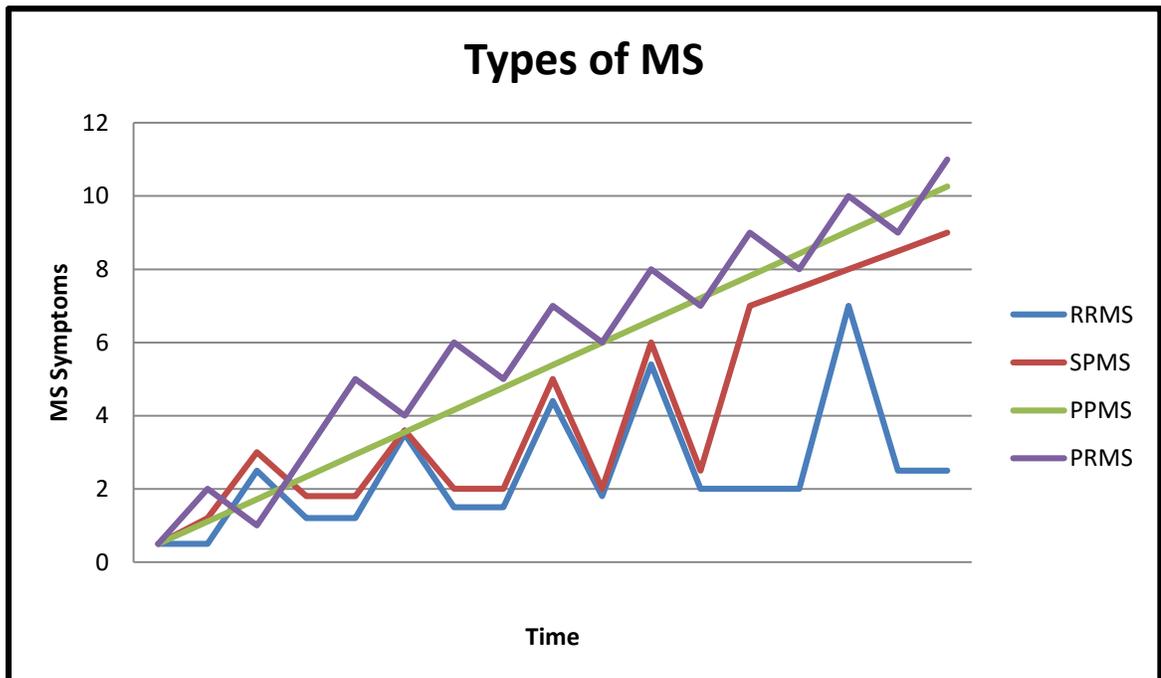


Figure 4. Graphical Representation of the Four Types of MS.

### Treatment Protocols for MS

MS progresses over time and there is no known cure. The only treatments currently available are designed to control symptoms to improve quality of life. MS can have a significant negative impact on both cognitive functioning and physical ability (Patti, 2009). The impact that this disease has on an individual's ability to function and live a happy and productive life varies greatly depending on the type and progression of

the disease, and it is imperative that early and effective treatments are implemented for individuals with MS. MS treatments have one of three goals (a) treating symptoms of an acute flare-up in order to return the patient to pre-flare-up functioning, (b) addressing long-term disease progression to slow the advancement, or (c) treating the secondary symptoms of MS such as numbness, vision problems, etc. (Halper & Holland, 1996; Iezzoni, 2010). Due to the varying nature of MS, treatment protocol options are also widely varied. Current treatment can be categorized into four basic categories, drug protocols, PA interventions, non-traditional medicine, and diet modifications (Halper & Holland, 1996). For the purposes of this examination we are going to briefly examine drug protocols and focus primarily on PA interventions. Diet modifications and non-traditional medicine are extremely multifaceted, still widely controversial, and often lack an evidence base; therefore they fall beyond the scope of this paper.

**Drug Therapies.** The three goals of drug therapies are treatment of acute flare-ups (symptomatic treatment), long term disease management – referred to as Disease Modifying Treatment (DMT), and secondary symptom control. This paper will briefly discuss the treatment protocol of acute flare-ups and long-term disease progression; it will not discuss treatments for secondary symptoms. The drug protocols that address secondary symptoms are numerous and do not directly relate to the focus of this examination.

An acute flare-up, also known as an exacerbation, is classified as any time an MS patient begins experiencing a heightened level of acute MS symptoms that they do not normally experience (Fleming, 2002; Kalb, 1996). It is important to get an exacerbation

under control quickly to minimize the neural damage that is occurring as lesions are forming in the nervous system (Halper & Holland, 1996). Acute flare-ups are treated with glucocorticoids, a four-ringed steroid molecule with strong anti-inflammatory and immunosuppressive qualities, with the purpose of hastening recovery from the exacerbation (Coyle & Hamaad, 2006; Wagstaff, 2000). Steroid use is not a long-term treatment option as the high doses necessary have a number of acute side effects including insomnia, extreme emotional fluctuations, fluid retention, weight gain, cardiac arrhythmia, hypertension, hyperglycemia, and increased susceptibility to infection (Coyle & Hamaad, 2006). Steroids can be administered orally or intravenously with both methods appearing to elicit similar results in controlling exacerbations (Wagstaff, 2000).

Long-term treatments for MS focus on altering the immune system response to the disease. Current DMTs rely on the assumption that MS is an autoimmune disease that is attacking the body's nervous system. As such, the goal of DMT is to control the immune system response to the perceived threat to the body (Coyle & Hamaad, 2006; Fleming, 2002; Wagstaff, 2000). The current DMTs include immunomodulators (drugs that modulate the immune system response in some way) and immunosuppressives (drugs that specifically slow or inhibit the body's natural immune system response) (Kalb, 1996). Immunomodulators are the most commonly used DMT for treating MS because they are less destructive to the immune system as a whole. Immunomodulators tend to be more focused on specific types of immune system functions while leaving other types of functions intact (Talley, 2008). Typically immunosuppressives are a last resort for patients who are not responding to standard immunomodulator treatments

(Coyle & Hamaad, 2006; Kalb, 1996). Immunosuppressives can be very effective in the control of MS progression but do leave the patient more susceptible to other infections (Talley, 2008).

It is important to realize that the success of DMTs is primarily limited to patients with RRMS. Once the disease progresses to SPMS or takes the form of PPMS or PRMS the effectiveness of these therapies is marginal at best (Fleming, 2002). It is for this reason that it is imperative to find ways for patients to remain in the RRMS phase of their disease as long as possible. Once MS progresses, treatments and control are not nearly as successful. In conjunction with drug therapies, another means to delay MS progression is through the incorporation of a PA protocol.

**Physical Activity.** PA is defined as anything that increases heart rate, incorporates large muscle group movement, and gets the body moving (“Physical Activity Guidelines for Adults,” 2014). There is a growing body of research surrounding the implementation of PA as a supplemental treatment for MS patients who are sedentary (White & Dressendorfer, 2004). A review of this research shows that muscular strength, aerobic capacity, walking performance, quality of life, fatigue, balance and gait are all improved (Motl & Pilutti, 2012). For example, research by Levy, Li, Cardinal, and Maddalozzo (2009) demonstrated a significant reduction in physical symptoms in sedentary female MS patients when the patients exercised for one year. Dalgas et al. (2009) showed improvement in functional strength and capacity in moderately impaired MS patients after a 12-week lower extremity strength program. A recent meta-analysis showed small but significant improvements in walking mobility in patients who

participate in exercise programs of all types (Snook & Motl, 2009). This research all points to symptom improvement when PA is incorporated into the lives of individuals with MS, for this reason, exploration into the specifics surrounding PA protocols needs to continue to be a focus.

PA also has a direct effect on frequency, intensity, and duration of MS symptoms (White & Dressendorfer, 2004). Specifically, PA has been shown to reduce MS flare-ups (Motl & Snook, 2008; Petajan et al., 1996). There is also growing evidence that long-term PA aids in slowing the progression of MS. Stuifbergen, Blozis, Harrison, and Becker (2006) demonstrated a significant reduction in long-term disease progression in patients who exercised for a 5-year period. This research points to reasons why it is beneficial for PA to be incorporated into the lives of individuals living with MS.

Increased fatigue is a symptom often seen in individuals with MS; however research has shown that overall fatigue levels are not affected by PA participation, meaning that PA can be incorporated into daily activity without concern for increased fatigue (van den Berg et al., 2006). A recent meta-analysis found a reduction in overall fatigue levels in individuals with MS when they were placed on an exercise program suggesting that PA could actually be used as a means to decrease fatigue levels (Pilutti, Greenlee, Motl, Nickrent, & Petruzzello, 2013). Fear of increased fatigue levels is often cited as one of the reasons that individuals with MS shy away from PA; thus, the aforementioned research showing a decrease in fatigue is promising for PA interventions (Lee, Newell, Ziegler, & Topping, 2008).

In addition to physical benefits, there is some evidence that PA participation may increase cognitive functioning, psychological coping skills, and overall quality of life in MS patients, although findings are mixed. Motl, Gappmaier, Nelson, and Benedict (2011) examined the association between PA and various cognitive functions in MS patients. They found that an intervention that increased PA in sedentary MS patients correlated with improved cognitive processing speed. This research suggests that PA may be beneficial as a treatment for the cognitive impairments of MS as well as for the physical impairments.

*PA recommendations for individuals with MS.* A systematic review of PA interventions with MS patients established recommended PA guidelines for adults with mild to moderate MS; these guidelines recommend a minimum dose of PA required to improve fitness, increase mobility, improve QOL, and decrease fatigue (Latimer-Cheung et al., 2013). The specific recommendations are at least 30 minutes of moderate intensity aerobic exercise twice per week and strength training for all the major muscle groups at least twice per week. Currently only a small number of individuals with MS report meeting these guidelines (Klaren, Motl, Dlugonski, Sandroff, & Pilutti, 2013). Current recommendations from the ACSM (2002) suggest the same amount of PA for individuals with MS and other chronic neurologic diseases as is recommended for the general public – 30 minutes of PA most days with both aerobic and strength workouts included. Although these two sources for PA recommendations are not exactly the same, they both similarly prescribe regular aerobic and strengthening exercises and suggest that the guidelines are the minimum necessary for health benefits. In addition to these

recommendations, stretching may be important for MS patients because of the limited range of motion that is often experienced due to muscle spasticity (American College of Sports Medicine, 2002).

*Special considerations in PA prescription for MS patients.* The American College of Sports Medicine (ACSM) (2002) suggests some special considerations when incorporating a PA program into the lives of individuals with MS. Heat sensitivity is a big concern in the daily lives of the vast majority of MS patients (Iezzoni, 2010). Increases in external (environmental air temperature) and/or internal (body) temperature magnifies MS symptoms, especially increasing fatigue and coordination problems (American College of Sports Medicine, 2002). It is recommended that PA be limited to locations where ambient air temperature is cool and that aerobic PA be limited to moderate intensity to prevent overheating. Climate controlled gyms and temperature controlled swimming pool workouts may be good options for this. The ACSM (2002) also suggests that PA be focused on the individual's physical capabilities. Coordination problems are often seen in MS patients; for this reason it may become necessary to alter both aerobic exercise (e.g. stationary bicycle versus treadmill) and strength exercises (e.g. weight machines versus free weights) in order to accommodate physical limitations and promote successful participation for the individual (ACSM, 2002). Sensory perception is also sometimes lost or diminished in MS patients; in conjunction with coordination issues this can pose a safety issue while participating in certain activities. For this reason, it is recommended that any individual with MS is closely supervised when introduced to new forms of PA to insure they can safely execute the activity (ACSM, 2002).

## **Quality Of Life Benefits of PA in MS Patients**

There is a growing body of research surrounding quality of life benefits from PA participation in MS patients. Individuals who are physically active report increased physical and cognitive ability and this can translate into higher reported quality of life (Motl & Snook, 2008). For instance, Motl and McAuley (2009) found in a 6 month study using accelerometer data that individuals who were more active reported improved quality of life, a reduction in pain and fatigue, and an increase in social support and self-efficacy. After a PA intervention using progressive weight training, women with MS reported improvements in strength, walking ability, and daily activity functioning. In qualitative interviews, these women all reported an increased quality of life with the perception that this was a result of these physical improvements (Giacobbi, Dietrich, Larson, & White, 2012). Physical activity has also been reported to increase psychological quality of life through interventions that increased self-efficacy in participants (Motl, McAuley, Wynn, Sandroff, & Suh, 2013). In contrast to the above findings, Romberg, Virtanen, and Ruutiainen (2004) did not find significant improvements in reported quality of life in MS patients after a PA intervention, even when participants reported functional improvement. The research by Romberg and colleagues only examined physical quality of life changes from PA participation and did not focus on quality of life factors associated with cognitive improvements or psychological constructs. It is possible that this is the reason that there was not a reported increase in quality of life. It appears that most research points to improvements in both

physical and cognitive functioning through PA participation and this can have a significant impact on overall quality of life (Ellis & Motl, 2013).

In conjunction with this increased quality of life, a positive attitude and a positive mental approach have been linked to reductions in MS symptoms (Motl & Snook, 2008). MS patients with a positive outlook about their disease have been shown to have a reduction in the number of flare-ups they experience over time (Levy, Li, Cardinal, & Maddalozzo, 2009). MS patients are prone to depression and as a population exhibit higher than average levels of depression and other similar psychological disorders (Pakenham, 2006). Positive life experiences reduce depressive symptoms in MS patients. The more positive life experiences they reported, the less depression they reported, regardless of their level of functioning (Phillips & Stuifbergen, 2008). Collectively, this research suggests that when exercise is a positive experience, it can improve quality of life.

A recent meta-analysis of the research confirms this positive impact of PA on quality of life (Motl & Gosney, 2008). It appears that PA could play a role in symptom management and, consequently, positively influence overall quality of life (Motl & Pilutti, 2012). Participants in PA programs report higher levels of functioning and overall quality of life than non-physically active controls (Sutherland, Andersen, & Stoové, 2001). Furthermore, when exercise improves physical performance, self-efficacy also improves (Motl & Snook, 2008). This scenario creates a PA – self-efficacy cycle that propagates itself to create an improved QOL. Considering all of the findings surrounding PA and physical, cognitive, and psychological benefits in tandem, it seems that

intervention in the form of a PA protocol is important in order to maintain mobility as long as possible and increase improvements in long-term prognosis.

### **Physical Inactivity and the MS Population**

The aforementioned body of research would suggest that PA should be an integral part of treatment for individuals with MS. Contrary to this, individuals with MS are a largely sedentary population (Sandroff et al., 2012). As discussed, PA has been shown to help minimize both physical and cognitive MS symptoms and increase quality of life. Unfortunately, due to the physical limitations experienced as a result of MS, many individuals avoid PA after diagnosis with MS (Motl & Snook, 2008; Petajan et al., 1996). Individuals with MS are less physically active than the general population and less active than individuals with other chronic conditions such as diabetes and Parkinson's disease (Motl, McAuley, & Snook, 2005; Nortvedt, Riise, & Maeland, 2005). Research indicates only 19.5 % of individuals with MS report meeting the public health guidelines for moderate to vigorous PA (Klaren et al., 2013). Additionally, the less ambulatory the MS patient is, the less likely they are to participate in PA (Klaren et al., 2013). The problematic nature of this juxtaposition of PA and mobility suggests an inactivity cycle that propagates itself; the individual is physically inactive because of limited mobility and the lack of PA contributes to the reduction of mobility.

High levels of self-efficacy have been shown to have a positive effect on MS patients' motivation for PA participation (Dlugonski, Motl, Mohr, & Sandroff, 2012; Ellis & Motl, 2013). Individuals with MS who report higher self-efficacy for PA also report higher levels of PA participation, and PA interventions that have been designed

around increasing self-efficacy are more successful than interventions that are only based on PA participation without the self-efficacy component (McAuley et al., 2007; Motl, Dlugonski, Wójcicki, McAuley, & Mohr, 2011). For this reason, it is imperative that any PA interventions include a focus on psychological motivators as well as perceived physical benefits.

### **Theories of Behavior Change**

When examining behavior motivation, it is important that a theoretical framework is used to guide understanding and methodology. A great deal of recent literature on motives for PA participation has centered on cognitive theories (Dugdill, Crone, & Murphy, 2009; Roberts & Treasure, 2012; Young et al., 2014). For the purposes of this review, two of these theories will be explored: Social Cognitive Theory (SCT), which has encompassed most of the existing theoretical behavior change research specific to MS and PA (Motl, 2014), and Self-Determination Theory (SDT), which the current research posits may be a better theoretical model for determining motivational outcomes in MS patients.

#### **Social Cognitive Theory**

According to SCT, there are certain psychological variables that are necessary for any health behavior to occur (Bandura, Adams, & Beyer, 1977). One of the variables that is a proven method of increasing PA participation is self-efficacy (Bandura, 1997). Self-efficacy is the belief of the individual that they are competent and confident in successfully executing a given task in a given situation (Bandura et al., 1977). Self-efficacy is situation specific and varies according to the perceptions the individual has

surrounding his or her abilities to execute the task. Accordingly, individuals have a tendency to engage in activities that they feel they can be successful at, including PA behaviors (Bandura, 2004; Young et al., 2014). This self-efficacy then increases the individual's outcome expectations for the behavior in question (in this case PA participation) and motivation for continuation of the behavior results. Based on SCT, if we can increase self-efficacy in sedentary individuals in order to facilitate confidence in PA ability, we will increase PA participation. Furthermore, individuals who are physically active should exhibit high levels of self-efficacy for PA and have strong outcome expectations for successful participation.

In support of SCT as a predictor of motivation for behavior, self-efficacy has been shown as a correlate of PA in individuals with MS (Suh, Weikert, Dlugonski, Balantrapu, & Motl, 2011; Young et al., 2014) and SCT theory has been repeatedly used to successfully create and implement behavior change interventions in individuals with MS (Motl, 2014). Interventions where participants received SCT-based information via phone and newsletter showed significant increases in PA participation (Suh, Motl, Olsen, & Joshi, 2015). An 18-month longitudinal study to assess social cognitive variables showed that a significant change in self-efficacy and goal setting had an indirect effect on PA participation, supporting SCT as an effective means for changing behavior (Suh et al., 2011). In relation to physical wellness and SCT, results from a 6-month longitudinal study showed that after a 3-day, intensive, multidisciplinary, social-cognitive wellness intervention, participants showed improved self-efficacy and enhanced autonomy for wellness behaviors 6-months post-intervention (Jongen et al., 2014). Examining the

relationship between symptoms, PA, and self-efficacy using SCT shows a positive relationship between self-efficacy and PA, and a negative relationship between symptoms and PA and symptoms and self-efficacy (Motl, Snook, McAuley, & Gliottoni, 2006). All of this research points to SCT as an effective predictor of PA participation in individuals with MS and an effective theoretical background for designing interventions.

### **Self-Determination Theory**

It can be argued that SDT is similar to SCT in assessing quantity of motivation, the difference being that SDT is also focused on the type of motivation. As previously discussed, SCT views motivation as a singular construct with variation in only the quantity of motivation (Standage & Ryan, 2011). In contrast, SDT is a theory of behavior motivation based on varying levels of both quantity and type of motivation (Deci & Ryan, 1985, 2004; Standage & Ryan, 2011). When looking at motivation, SCT asks “how much”; SDT asks “how much and what kind?” By examining both the amount and type of motivation, SDT allows for a more detailed analysis of the drive for behavior.

SDT posits that people have a natural desire to behave in an effective and healthy way – the driving force behind this behavior is self-determination (“selfdeterminationtheory.org — An Approach to human motivation & personality,” 2015). The more self-determined an individual is, the more internalized the motivation for behavior. Self-determination is realized through satisfying the basic need for competency, autonomy, and relatedness. If individuals feel competent at what they are doing, feels they are doing it as their own choice, and feel related to others in the same behavior, then the behavior becomes self-determined and will continue (Deci & Ryan,

1987). Deci also argues that autonomy is the most important of these three constructs and as such, has spent the last 20 years developing ways to isolate the best methods to develop an autonomy supportive climate in hierarchical situations (Deci & Flaste, 1996).

According to SDT, the key to understanding behavior is understanding the type of motivation the individual possesses. More specifically, SDT asks where the motivation for the activity originates. It is not enough for the individual to feel self-efficacious for the ability to complete a behavior, the self-efficacy also needs to come from a (personally-determined) sense of autonomy in the behavior. The more autonomous an individual is, the more internal (self-determined) the motivation for the activity. As autonomy is removed, the motivational source for the activity becomes more externally influenced and less self-determined. An example of this is the individual who is participating in PA because they are being told to do so by someone else. They may have confidence that they can be active (high self-efficacy) but because their motivation is externally controlled, the likelihood that PA is going to remain a lasting behavior is reduced. Motivation in SDT is measured on a continuum. The SDT motivation continuum ranges from amotivation (lack of motivation for the activity) to extrinsic motivation (motivated by external forces), to intrinsic motivation (performance of the activity for the enjoyment of the activity) (Frederick-Recascino & Schuster-Smith, 2003). Extrinsic motivation is a multidimensional construct that is divided into four levels: external regulation, introjected regulation, identified regulation, and integrated regulation. These levels represent a continuum of self-regulation which spans from complete external regulation to almost completely internal regulation (Ryan & Deci, 2000). The

more internally regulated the motivation, the closer the individual is to an intrinsic motivation for participation. An individual does not exhibit complete internal regulation of their motives for participation in their activity until they are intrinsically motivated. See Table 1 for brief definitions of the complete motivation continuum and Table 2 for a visual representation of this continuum.

*Table 1. Brief Definitions of SDT Levels of Motivation*

Motivation level:	Definition:
Amotivation	No motivation for the activity
External regulation	Motivated by outside sources (doctor's orders)
Introjected regulation	Motivated by obligation (guilt)
Identified regulation	Motivated by activity benefits (fitness gain)
Integrated regulation	Motivated by identification (I am a...)
Intrinsic motivation	Motivated by the enjoyment of the activity

*Table 2. Motivation Continuum*

Amotivation	Extrinsic Motivation			Intrinsic Motivation
External Regulation	Introjected Regulation	Identified Regulation	Integrated Regulation	
<i>&lt;--Continuum of Self-determination --&gt;</i>				

It is important to understand the motivation continuum in order to fully grasp SDT. Knowing how self-determined the individual is will provide the information necessary to answer the research questions. This project uses both global self-determination and the motivation continuum to assess motivation. The more self-determined the individual is the closer they fall to the intrinsic end of self-determination and therefore the more likely they are to participate in PA.

## **SDT and PA**

SDT has been used in numerous settings to effectively assess motivation for behavior. Specific to the purpose of this research, SDT has been shown to be an effective means for evaluating motivation for PA participation in numerous settings (Standage & Ryan, 2011). For instance, in breast cancer survivors, SDT has been shown to account for 20% of the variance in PA participation and was considered a useful predictor in understanding PA participation in this population (Milne, Dodd, Guilfoyle, Gordon, & Corneya, 2008). Autonomous motivation (self-determined motivation) has been found to predict PA participation in a number of different populations including pregnant women (Gaston, Wilson, Mack, Elliot, & Prapavessis, 2013), cancer survivors (Wilson, Blanchard, Nehl, & Baker, 2006), overweight individuals (Silva et al., 2010), and at-risk children (Curran, Hill, & Niemiec, 2013). A systematic review of 66 studies consistently showed high levels of self-determined motivation for PA in individuals who were more autonomous in their participation. According to the findings of this review, the more self-determined the individual is, the more likely it is they will maintain long-term PA participation (Teixeira, Carraça, Markland, Silva, & Ryan, 2012). Collectively, this research provides support for the continued use of SDT as a valuable and effective means of examining motivation for PA. For this reason, it is appropriate to use SDT in this project as a means to examine PA motivation.

## **Research Using SDT to Examine PA in MS Patients**

Leading up to the current research, two previous projects examined PA motivation in MS patients using a SDT framework. A 2013 case study with one highly

physically active woman with MS explored the role of athletic participation in her life (Fasczewski, Gill, & Barrett, n.d.). This case study was designed to gain insight into how self-perceptions and psychological skills aided the individual in meeting the challenges posed by her disease. The participant was a 51-year old competitive elite amateur mountain bike racer who was diagnosed with MS when she was a teenager. Results suggest that she saw high self-efficacy, mental toughness and a positive outlook as keys to success in sport and in life, and that her participation in athletics strengthened her overall quality of life.

Although SDT was used as a framework for the analysis of the aforementioned case study, the open-ended interviews left many unanswered questions regarding motives for PA participation. In order to examine these questions further, a second study, designed as a pilot study for the current project, was done to explore the use of specific SDT measures with the MS population. This pilot study examined a larger sample of highly active people with MS. Self-efficacy and the basic needs of competence, autonomy and relatedness, and quality of life were explored as they relate to motivation and participation in high levels of PA using surveys and semi-structured interviews (Fasczewski, Gill, & Rothberger, n.d.). The interviews focused on a) motivation and strategies used to maintain physical activity, and b) the benefits and impact of PA in their lives. All participants were highly motivated to participate in PA, and the main themes were in line with SDT; participants described feelings of accomplishment and competence in both their PA and daily life, as well as a sense of independence and

autonomy. All participants also reported high overall quality of life and attributed this in part to their PA participation.

The results from these projects provided insight into the motives for PA participation in an active sample of people with MS and lend support for future research using SDT as a framework for understanding this motivation. It now becomes important to expand this research to understand these motives for the entire MS population. This is the first step in developing a SDT-based PA intervention.

### **Summary**

This project is unique because it explores PA motivation in the MS population through the lens of SDT and self-efficacy. It is especially relevant because the MS and PA research that has been done previously relies on SCT as a theoretical backdrop. SDT can provide an additional, in-depth examination of the motives for PA participation that cannot be gained through solely using SCT by explaining both the amount and type of motivation. Modeling this relationship will allow for the development of future interventions with MS patients by lending insight into the important aspects of this relationship. Before any intervention can be developed, the relationship between SDT and PA participation needs to be understood; and that is what this project is designed to do. Finding ways to promote PA within this population is an important part of disease management long-term for these individuals. Through this type of understanding and eventual intervention, disease symptoms can be better controlled and therefore overall quality of life will be enhanced for MS patients.

## CHAPTER III

### METHODS

The purpose of this study is to examine self-determined motivation, self-efficacy, PA participation, and quality of life in individuals with MS. Specifically, structural equation modeling techniques were used to model the relationships among self-determined motivation, self-efficacy, PA, and quality of life. Survey methods were used with a large sample of people with MS to obtain measures of motivation, PA, and quality of life.

#### **Participants**

The original plan for recruitment relied on using mass email distribution from the North American Research Committee on Multiple Sclerosis (NARCOMS) registry. The NARCOMS registry is a voluntary, self-report registry where individuals with MS complete an enrollment questionnaire and biannual surveys and then can be identified by the registry as potential research participants in projects that are applicable to the individual. NARCOMS was contacted with study details and participant parameters upon receipt of IRB approval. Unfortunately, NARCOMS was unable to provide access to their database in a timely manner; they offered assistance beginning in August of 2016. Due to the timely nature of the project, the National Multiple Sclerosis Society (NMSS) was contacted regarding research assistance. The NMSS approved the study for distribution

and posted information and the survey link on the NMSS website ([www.nmss.org](http://www.nmss.org)) under the ongoing research page. Additionally, all 34 NMSS regional chapters were contacted via email explaining the study and asking for assistance in distribution. Nine chapters responded and agreed to help; of those 9, 6 (North Carolina/South Carolina, Georgia, Alabama, Ohio, Northern California, Gateway Area) sent the link directly to support groups for distribution directly to members and 3 (New England, Indiana, NY City/Southern New York) placed the link in email blasts/monthly newsletters. Concurrently, a social media flyer was shared via Facebook ([www.facebook.com](http://www.facebook.com)). This flyer was posted as a “public” flyer, meaning that it could be seen and shared by anyone on Facebook. It was shared by 37 different individuals.

Participants were individuals between the ages of 18 and 65 years who have had MS for at least 1 year. This one-year requirement was to insure that they are not still in the initial acute flare-up that prompted diagnosis and have had time to live with MS. Because MS impacts each individual differently, there was no reason to restrict age for symptom-related reasons and individuals at any age can be physically active. Targeting this wide age range increased the likelihood of obtaining more data to increase statistical power, leading to meaningful, generalizable results. There was no restriction on disease progression, form, or PA level.

### **Measures**

Established measures of disease step, self-determination, self-efficacy for PA, and quality of life were used to assess the main variables. Basic demographic measures (age,

gender, disease step, time since diagnosis) were also used. Open-ended questions about PA, MS, and quality of life were included to allow participants to tell their experiences in their own words.

### **Disease Assessment and Physical Abilities**

**Patient-Determined Disease Step (PDDS)** – The PDDS is a single question ordinal scale that asks participants to self-rate the severity of their disease symptoms from 0 – Normal: “I may have some mild symptoms, mostly sensory due to MS but they do not limit my activity. If I do have an attack, I return to normal when the attack has passed” to 8 – Bedridden: “Unable to sit in a wheelchair for more than one hour” (Hohol, Orav, & Weiner, 1995, 1999). Each of the 9 PDDS rating numbers (0-8, higher being more disabled) corresponds with a description of that disability rating and the patient is asked to rate their disease symptoms as closely as possible to the descriptions provided. The PDDS was developed as a self-report reflection of the clinical standard Expanded Disability Status Score (EDSS) neurological assessment done by physicians. The EDSS is an in depth neurological physical exam that provides medical personnel with an overall rating number between 0 and 10 with the higher number being more disabled (Kuttzke, 1983). Using the PDDS is an effective method to gather similar information in self-report situations. Validation of the PDDS has determined that it is an effective alternative means for assessing disease step for patients with MS (Learmonth, Motl, Sandroff, Pula, & Cadavid, 2013). It has been used extensively by the Exercise Neuroscience Research Lab at the University of Illinois (one of the leading labs in the US for MS research) for this

purpose. Overall PDDS and EDSS scores were highly correlated ( $r = .783$ ), making it a viable tool for determining patient reported outcomes of MS symptoms in survey research (Learmonth et al., 2013). For this project, the PDDS was used to categorize individuals into two groups – the first group can be classified as minimally disabled individuals (scores 0-3), and the second group as functionally disabled individuals (scores 4-8). The decision to dichotomize these results was based on previous research that shows a significant drop in PA participation when individuals reach a disability level that limits functional mobility (Klaren et al., 2013). The cut off on the PDDS for mobility is between 3 and 4.

### **Physical Activity Level**

**Godin Leisure-Time Physical Activity Questionnaire (Godin)** – The Godin is a 3-question, self-report measure that assesses the frequency that individuals engage in bouts of PA at light, moderate, and strenuous levels (Godin & Shephard, 1985). The measure asks frequency of PA at each activity level and uses a formula to calculate a score (MET value) for weekly activity (9 x strenuous, 5 x moderate, and 3 x light). The higher the overall score, the greater the PA level. The MET scores can also be used to classify PA participation into three categories: “active” (24 and higher), “moderately active” (14-23), and “insufficiently active” (less than 14). More recently, research has proposed using only using the moderate and strenuous calculations to classify individuals as “active” ( $\geq 24$  METS) and “insufficiently active” ( $\leq 23$  METS) to fall in line with PA guidelines in both the United States and Canada (Amireault & Godin, 2015; Godin,

2011). For the majority of analyses in the current research, the total MET score as a continuous variable will be used. It is also important to know if participants who report being active (when asked “are you physically active”) are really participating in the recommended amount of moderate to vigorous PA as defined by MET scores. To understand this, participants will be classified as active and inactive. The Godin measure has good test–retest reliability (.84) (Godin & Shephard, 1985) and reviews of PA measures support its use (e.g., Jacobs, Ainsworth, Hartman, & Leon, 1993). It is one of the leading self-report measures of PA (Godin, 2011).

### **Self-Determined Motivation**

#### **The Behavioral Regulation in Exercise Questionnaire – Version 2 (BREQ-2)**

– The BREQ-2 is a multidimensional scale based on the motivation continuum in SDT, it includes amotivation (not motivated at all), external motivation (motivated by rewards and punishments), introjected motivation (motivated by feelings of guilt or self-worth), identified motivation (motivated by the value and importance of the activity to personal goals), and intrinsic motivation (motivated by the inherent enjoyment of the activity) (Markland & Tobin, 2004). The BREQ-2 is measured on a 5 point Likert-Type scale with 5 being high, each subscale has 4 questions except for the introjected regulation scale which only has 3 questions and is calculated individually for examination of the different levels of motivation. The Cronbach’s alpha for each subscale was reported as follows: amotivation (.83), external motivation (.79), introjected regulation (.80), identified (.73), and intrinsic motivation (.86), showing good internal consistency for all subscales

(Markland & Tobin, 2004). Results from confirmatory factor analysis indicate the BREQ-2 scale had good factorial validity with all the factors loading moderate to strong ( $M = .76$ , range = .53-.90;  $p$ 's < .001) (Markland & Tobin, 2004). Integrated regulation (motivated by identification with the activity) is clearly absent from this scale. This is because many researchers have been unable to distinguish between integrated regulation and intrinsic motivation in PA (Mallett, Kawabata, Newcombe, Otero-Forero, & Jackson, 2007). During the development of the BREQ-2 these two constructs could not be reliably individually determined (Markland & Tobin, 2004). There has been some recent evidence of development of a reliable scale for integrated regulation (McLachlan, Spray, & Hagger, 2011) but results have been limited and there is currently little support for using it with specialized populations. For this reason the BREQ-2 was used as designed with the 5 subscales.

**Self Determination Scale (SDS)** – The SDS is a 10-item scale with two, 5-item subscales. The subscales, sense of self and perceived choice in one's actions, can be used individually or combined for an overall self-determination score (Sheldon & Deci, 1996). The SDS assesses individual differences in the manner in which people function in self-determined ways. Each item is a pair of scenarios that contradict one another (e.g., I am free to do whatever I do; what I do is often not what I'd choose to do). The responses are measured on a 5-point scale with each pair of scenarios scored from 1 (only A feels true) to 5 (only B feels true). See Figure 5 for sample questions. According to SDT, the more self-determined an individual is, the more intrinsically motivated they are for the

behavior in question (in our case PA) and therefore the more likely they will participate (Deci & Ryan, 2004). The SDS has demonstrated good internal consistency, with alphas ranging from .85 to .93, adequate test-retest reliability (.77), and has been widely-used (Sheldon, Ryan, & Reis, 1996). This scale was used as a measure of overall self-determination in all aspects of the individual's life. The SDS was included in the analyses to examine self-determination as a global trait, unlike the BREQ-2 that examines self-determination as a more situation-specific trait. This difference is important to consider because overall quality of life could be impacted differently depending on the nature of self-determination, for this reason both scales were used.

SDS Example Question – Perceived Choice						
<i>A. I always feel like I choose the things I do.</i>			<i>B. I sometimes feel like it's not really me choosing the things I do.</i>			
Only A feels true	1	2	3	4	5	Only B feels true

SDS Question – Sense of Self						
<i>A. I feel that I am rarely myself.</i>			<i>B. I feel like I am always completely myself.</i>			
Only A feels true	1	2	3	4	5	Only B feels true

Figure 5. Example of SDS Question Style and Format

### Self-Efficacy

**Exercise Self-efficacy (EXSE)** – Self-efficacy for PA participation was assessed using the EXSE scale. It is an 8-item scale that asks subjects to rate the confidence in their ability to continue to participate in 40 minutes of continuous moderate exercise 3-times per week from 1 week to 8 weeks in the future (McAuley, 1993). The EXSE uses a

100-point percentage scale in 10-point increments (0% - not at all confident to 100% - completely confident) for each item. Self-efficacy is then calculated by summing the ratings and dividing by the total number of items on the scale with a maximum possible score of 100 (“Exercise Psychology Lab,” n.d.). The scale was developed to assess exercise self-efficacy in older adults but has been validated for use with the MS population (McAuley, Motl, White, & Wójcicki, 2010). The scale assesses self-efficacy in a longitudinal way, meaning how confident the individual is that they will continue to participate in PA over time.

**Markus Self-Efficacy for Physical Activity Scale (MSES)** – In addition to the EXSE, the MSES was used to assess global self-efficacy for PA in certain common PA situations that could be seen as challenging (e.g., when the individual is tired, busy, the weather is poor) (Marcus, Selby, Niaura, & Rossi, 1992). The MSES is a 5-item measure that is designed to assess an individual’s confidence in ability to continue participating in PA in situations that may present challenges. Test-retest reliability has been demonstrated at .90 and it has shown adequate internal consistency at .82 (Marcus et al., 1992)

The combination of these two measures provides a good overall picture of PA self-efficacy. The EXSE examines self-efficacy in a longitudinal manner (over 8 weeks) could be problematic if an individual experiences regular flare-ups that limit PA at certain times. The MSES assesses self-efficacy for PA in global sense and with no timeline.

## **Quality of Life**

**The Quality of Life (QoL) survey** – The Quality of Life Survey (Gill et al., 2011) is a 32-item Likert-type scale that assesses quality of life with 7 subscales. The subscales are integrated (4 items), which reflects overall quality of life, along with social (5 items), spiritual (5 items), emotional (5 items), cognitive (5 items), physical (5 items), and activities of daily living (ADL)/functional (3 items) quality of life. The scale begins with the phrase: “How would you rate the quality of your...” followed by 32 individual completers which respondents rate from 1 (poor) to 5 (excellent). Gill et al. (2011) developed and then developed the 32-item QoL survey based on a multidimensional, positive health conceptual model. Confirmatory factor analyses supported the multidimensional structure and all sub-scales had good internal consistency, with alpha .76-.95 (Gill et al., 2011). Subsequent research (Gill, Reifsteck, Adams, & Shang, 2015) confirmed the factor structure, strong internal consistencies of all sub-scales, and also showed good test-retest reliabilities and correlations with matching scales on similar measures supporting validity. All 7 subscales will be used in the study. As Gill et al. (2015) suggested, the integrated QoL subscale reflects overall quality of life, while the other 6 QoL subscales reflect the domains or dimensions of quality of life. The subscales that are the most applicable to the current project are physical, functional/ADL, and emotional, as well as integrated QoL.

**Satisfaction with Life Scale (SWLS)** – The SWLS is a 5-item Likert-type scale with respondents reporting from 1 (strongly disagree) to 7 (strongly agree) (Diener et al.,

1985). The SWLS is a global measure of life satisfaction, which is similar to, and often used to measure, overall quality of life. Total satisfaction with life scores range from 5 to 35. The SWLS was developed from a 48-item self-report scale that included both positive and negative items. It was later reduced to 10 items, and after further validation, it was reduced to a 5-item single construct scale (Pavot & Diener, 2008). The 5 items have shown a strong test-retest correlation. A factor analysis determined that a single factor accounted for 66% of the variance, demonstrating a single construct was being tested (Diener, Inglehart, & Tay, 2012). As such, the SWLS is an effective measure of global satisfaction with life in the current project.

### **Open-Ended Items**

**Open ended responses** – Open-ended questions regarding the participants' experiences with MS, PA, and overall quality of life were included as exploratory measures. Questions, which are similar to ones used in the pilot study, are as follows: *Describe your overall quality of life, How does MS impact your life, What motivates you to be physically active, How does physical activity specifically relate to your MS, and How does physical activity relate to your overall quality of life?* These questions are designed to provide added insights by allowing participants to give more detailed explanations of the role PA plays in their lives.

### **Procedures**

All survey questions were built into an online survey using *Qualtrics* online survey software. After approval was received from the Institutional Review Board, data

were collected using the online survey. Participants were recruited from the NMSS regional chapters that agreed to distribute the survey by emailing an invitation to participate to all MS support group members. The email included a brief description of the study, a copy of the informed consent, and a link to the survey. Concurrently, a study description with link was placed on the NMSS website research page. Electronic flyers were posted in newsletters for regional NMSS chapters, and were distributed via the social media website *Facebook*. Participation was voluntary and no names or identifying information were collected on surveys.

The goal was to collect data from 400 participants, which represents slightly more than the 20:1 ratio of participants to variables that is deemed ideal for SEM techniques such as path analysis. An acceptable ratio of 10:1 is more often used in SEM due to sample size limitations (Kline, 2011). Data collection lasted 42 days in December 2015 and January 2016.

### **Data Preparation and Preliminary Analysis**

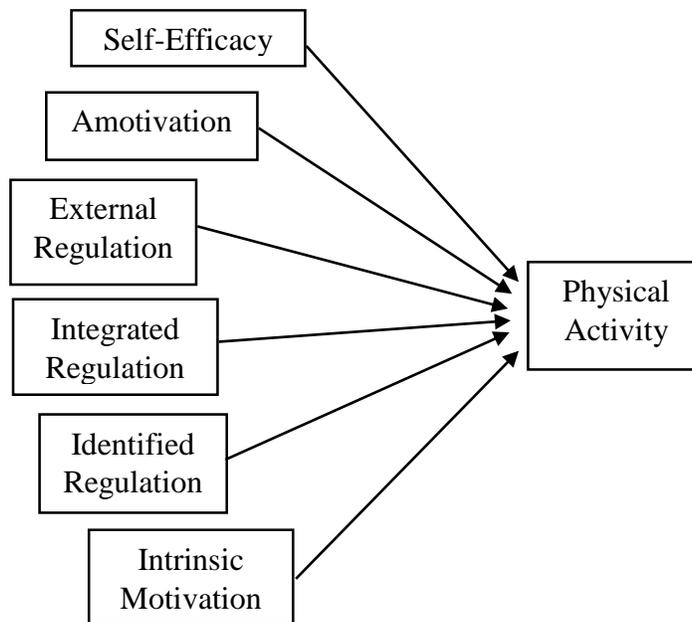
The data were first downloaded from Qualtrics into *SPSS Version 23* where data were cleaned by removing incomplete responses, confirming individual response format was correct for all respondents (e.g., a number of participants wrote out numbers – so instead of “2” they wrote “two”), and then calculating individual variable scores for survey scales and subscales. Data were also screened at this time for multivariate normality. Correlations of all measures were performed to examine all relationships. Multiple linear regressions was used to determine the contribution of the individual

predictor variables (EXSE, MSSE, QoL, and BREQ-2 subscales) to the relationship of self-determined motivation and self-efficacy to PA. Individual sub-scale predictors that were not significantly contributing to the relationships in the multiple regression did not need to be part of the main path analyses as they do not add information. These variables were removed from future analysis.

Confirmatory Factor Analysis (CFA) was used to test the structure of the BREQ-2 and QoL measures because measurement issues are very relevant in SEM analysis. CFA uses unit loading identifications, by setting a single loading to 1 for the unstandardized indicators, to assess overall structure of the scale. Fit indices used to determine fit are the chi-square goodness of fit, root mean square error of approximation (RMSEA), comparative fit index (CFI), and standardized root mean square residual (SRMS). The chi-square test of overall model fit should ideally not be significant, however chi-square is especially sensitive to small sample size which would include this project. For this reason the other fit indices were also examined. RMSEA accounts for parsimony in model fit. The value should be below .08 with the 90% confidence interval falling below .05 (good fit) or .10 (acceptable fit) (Kline, 2011). The CFI tests the proposed model against a null model for fit and should be above .90. The SRMR examines the difference between observed and estimated correlations and should be below .08 (Kline, 2011). Rarely do all fit indices agree on a given model and it has been suggested that as long as any two indices indicate good fit the model can be accepted (Hu & Bentler, 1999). When model fit was low, individual loadings and model fit indices were examined.

## **Data Analysis**

The main research questions were addressed using path analysis. The first part of the model and research question one, explored the relationship between self-efficacy, self-determined motivation, and PA. See Figure 6 for proposed path analysis for research question 1. LISREL 8 was used to conduct the path analysis. Path analysis is part of the family of SEM, which is a method of describing causal relationships among endogenous and exogenous variables (Vogt & Johnson, 2011). Path analysis simultaneously examines the strength of causal relationship in an overall theorized model. For research question 1, the model was specified as initially proposed in accordance with SDT, and all fit indices (chi-square, RMSEA, CFI, SRMR) were examined for goodness of fit. The individual unstandardized path loadings of the proposed model were examined for fit. Where poor model fit was indicated, respecification in accordance with existing theory was performed. It is important in path analysis that all respecification is driven by theoretical background in order to insure the results remain within the scope of the research question (Kline, 2011).



*Figure 6. Proposed Path Model of Self-Determination, Self-Efficacy, and PA*

Research question 2 focused on the relationship between PA and quality of life. Path analysis was again used to model the relationship between all QoL subscales and PA (see figure 7). Respecification was performed as necessary in the same manner as with research question 1. A separate model examined the 6 QoL subscales (physical, emotional, ADL/functional, cognitive, social, and spiritual) as predictors of the QoL Integrated mode to determine if the QoL measure should be included in the final model as a single construct or as multiple constructs. It was hypothesized that at least some of the individual QoL constructs and integrated QoL contribute to the model. See Figure 8 for representations of this model.

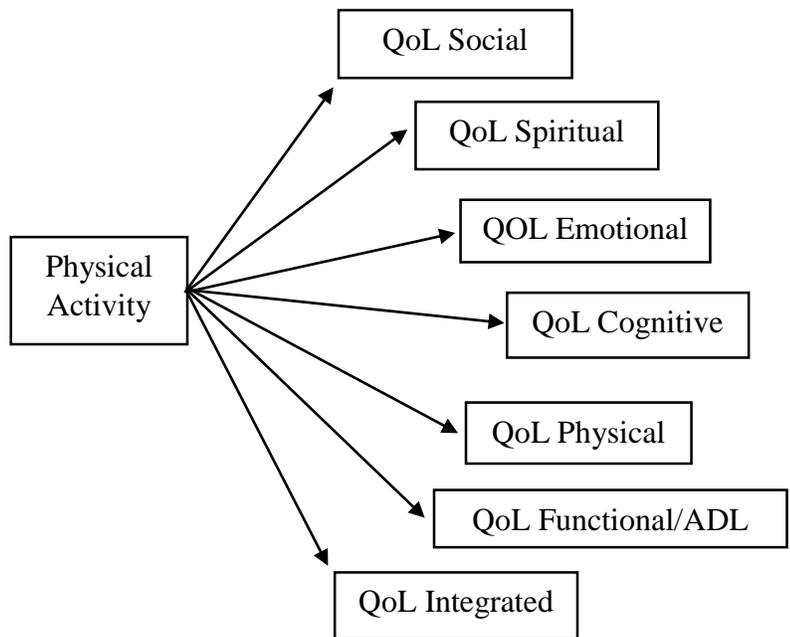


Figure 7. Path Model of PA – QoL Subscales

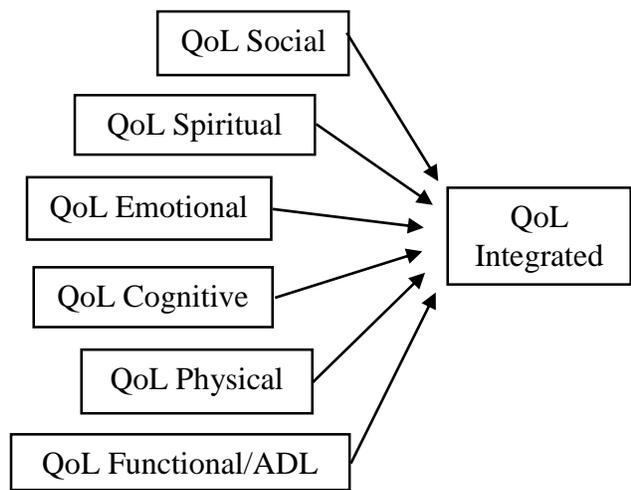
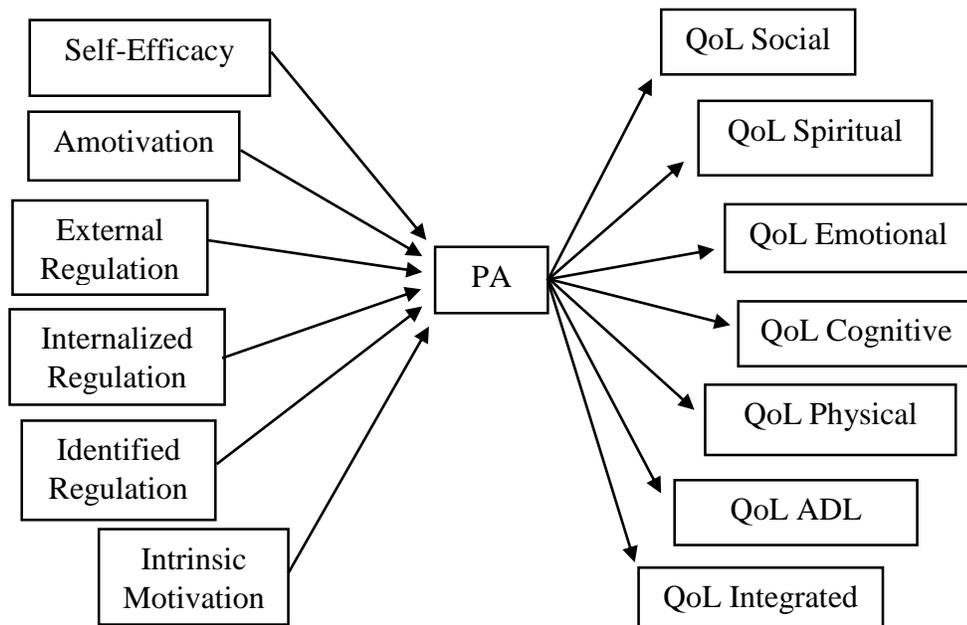


Figure 8. Path Model of the Multidimensional QoL Relationships

After the separate parts of the model from research questions 1 and 2 were examined, an overall path model was examined. This overall model includes the paths from self-determined motivation and self-efficacy to PA participation, and from PA to QoL. It was examined in the same way as the previous models and was respecified using logical, theoretical background as guidance. The proposed overall model is shown in Figure 9. During the examination of the overall model, Sobel's Test of Mediation was used to examination if the partial mediation between variables was significant (Sobel, 1982). This test specifically examines mediation in path analysis models.



*Figure 9. Path of Overall Model*

After the final overall model was respecified and confirmed, the model was run separately for low (PDDS 0-3) and high (PDDS 4-8) disease step groups, to see if the

models were equivalent across disability levels. This addressed research question 3. Crosstabs of PDDS and PA levels were also examined. In the examination of research question three, Chi-Square test of difference was also used to examine the relationship between the PA level and PDDS to give a better idea of the linear nature of the relationship.

## CHAPTER IV

### RESULTS

The purpose of this study was to explore the relationships among self-determined motivation, self-efficacy, PA participation, and quality of life in individuals with MS. This chapter reports basic demographics and relationships and then focuses on the results of the path analyses used to explore the research questions.

#### **Sample Demographics**

The sample consisted of 215 individuals between the ages of 18 and 65 years who had been diagnosed with MS at least one year prior to participation. The survey link collected 305 total responses; a response was categorized by Qualtrics as any individual who clicked on the survey link that took them to the informed consent and study description. Of the 305 responses, 50 were removed because they did not answer any questions and exited out of the survey without progressing past the informed consent and study description. The remaining 255 participated in at least a portion of the survey. The remaining dataset was still above the 10:1 ratio suggested by Kline (2011) so a decision was made not to include incomplete data (see Table 3). During the preliminary examination of results, 2 additional responses were removed because they did not report having MS, and 2 participants were removed because they were outside the specified age range, reporting ages of 73 and 80 years old. Both of these individuals were white males,

both had advanced progression of MS and both reported no PA participation (Table 3). The 215 remaining responses were used in the analysis of the research questions. Respondents had a mean age of 48.9 years ( $SD = 9.4$ ), with an average time with MS of 11.96 years ( $SD = 8.28$ ), were 80% female ( $n = 172$ ) and 20% male ( $n = 43$ ), and were predominantly white ( $n = 197$ ).

*Table 3. Explanation of Survey Dropout and Final Sample*

<b>Participants</b>	<b>Survey section</b>
305	Initial survey link
<b><i>Dropout – last section completed</i></b>	
50	Informed Consent
9	SDS
10	BREQ-2
1	PA type
11	ESSE
3	QoL
2	PDDS
219	Complete
4	Did not meet inclusion criteria
<b>215</b>	<b>Total Participants</b>

Due to the variability of MS, information was collected about the participants' current stage of MS (PDDS), flare up history, PA level currently and prior to diagnosis, and most common symptoms (tables 4 to 6). Participants reported PDDS scores across the range of the measure with 65.1% of participants reporting PDDS scores of 0-3 (not requiring mobility assistance) and 35.9% reporting PDDS scores of 4-7 (requiring some type of mobility assistance). No participants reported a PDDS score of 8 (bedridden) (Table 4; see Appendix A for a complete description of PDDS levels). A majority (67%) of participants reported 1 or fewer flare-ups per year and only 5.6 % indicated more than

9 flare-ups per year (Table 5). Almost half of participants (47.4%) had not experienced a flare-up in the past year. A small percentage (12.6%) had experienced a flare-up less than 1 month ago. No patients reported currently being in a flare-up (Table 5). PA levels before MS were high in this sample, with 87% of respondents reporting that they were physically active before they were diagnosed with MS. Almost two-thirds of respondents (62.3%) reported currently participating in some type of PA, duration and intensity not specified. An examination of the Godin PA data (which looks at moderate to vigorous intensity PA) reflected these self-report assessments of activity level, with 55.3% classified as insufficiently active, and 44.7% active (Table 6). When classified into defined activity (e.g., METs as specified by the Godin PA measure), PA levels reported by some individuals did not meet the guidelines and therefore although individuals reported were active, they were not sufficiently active to be classified as such by the Godin. This explains the discrepancy between the two current PA reported numbers.

*Table 4. Participant PDDS Scores*

<b>PDDS Score</b>	<b>Frequency</b>	<b>Percentage</b>
0	56	26.0
1	29	13.5
2	23	10.7
3	32	14.9
4	25	11.6
5	18	8.4
6	19	8.8
7	13	6.0
8	0	0

Table 5. Participant MS Flare-Ups per Year and Time Since Last Flare-Up

<b>Number of Flare-ups</b>	<b>Frequency</b>	<b>Percentage</b>
1 or less per year	144	67
2-3 per year	47	21.9
4-6 per year	12	5.6
9 or more per year	12	5.6
<b>Time Since Last Flare-up</b>	<b>Frequency</b>	<b>Percentage</b>
Less than 1 month ago	27	12.6
1-2 months ago	16	7.4
3-4 months ago	27	12.6
5-6 months ago	18	8.4
7-9 months ago	10	4.7
10-12 months ago	15	7.0
More than 12 months ago	102	47.4

Table 6. Self-Report PA before MS Diagnosis, PA Currently, and Godin PA Level

<b>Physically Active before MS?</b>	<b>Frequency</b>	<b>Percentage</b>
Yes	187	87
No	28	13
<b>Physically Active currently?</b>	<b>Frequency</b>	<b>Percentage</b>
Yes	134	62.3
No	81	37.7
<b>Godin PA</b>	<b>Frequency</b>	<b>Percentage</b>
≤ 23 insufficiently active	119	55.3
≥ 24 active	96	44.7

Participants reported a wide variety of symptoms as a result of MS and most reported multiple symptoms (Table 7). The most common symptom, fatigue, was reported by 50.7% of participants, and almost half (45.6%) reported gait/coordination/muscle weakness as a symptom. Most symptoms related to physical functioning. The only other reported symptom was emotional disturbances/depression (7% of participants). Only one participant reported not experiencing symptoms.

*Table 7. Most Common MS Symptoms Experienced by Participants*

<b>Symptoms</b>	<b>Frequency*</b>	<b>Percentage</b>
Fatigue	109	50.7
Gait/Coordination/Muscle Weakness	98	45.6
Neuropathy/Numbness/Tingling/Burning/Itching	73	34.0
Cognitive/Brain Fog/Memory Issues	66	30.7
Vertigo/Dizziness/Balance	43	20.0
Vision Problems	39	18.1
Pain	35	16.3
Bladder/Bowel	33	15.3
Stiffness/Spasticity/Cramping	27	12.6
Emotional Disturbances/Depression	15	7.0
Heat Intolerance	8	3.7
Insomnia	6	2.8
Speech Problems	6	2.8
Headache	6	2.8
Breathing/Swallowing Difficulties	4	2.0
MS Hug (tightness in chest cavity)	4	2.0
Sexual Dysfunction	2	1.0
Tremors	2	1.0
Seizures	2	1.0
Ringing in Ears	1	0.4
Stomach/ Digestive Issues	1	0.4
Weight Loss	1	0.4
Dysautonomia	1	0.4
Increased Blood Pressure/Heart Rate	1	0.4
None	1	0.4

*\* Most participants reported more than one symptom*

### **Preliminary Analyses**

Prescreening indicated the data were roughly normally distributed, with very little skew and kurtosis, pointing to multivariate normality among the data and meeting the assumption of multivariate normality. This is important because in maximum likelihood estimation, it is essential to obtaining a well-fitting model (Kline, 2011). Confirmatory Factor Analysis was used to examine the factor structure of the BREQ-2 and QoL scales.

Four indices of model fit were used to assess goodness of fit (Chi-square, RMSEA, CFI, SRMR) and fit was determined to be good if any two fit indices demonstrated a well-fitting model (Hu & Bentler, 1999).

The BREQ-2 was modeled with all 5 subscales and the result demonstrated poor fit,  $\chi^2(5) = 75.12, p < .01$ ; RMSEA = .255 (90% Confidence interval .21 - .47); CFI = .070; SRMR = .128. An examination of the literature on the development of the BREQ-2 scale reveals the Amotivation subscale demonstrated some reliability issues due to range limitations. Researchers decided to include it in the measure but suggested further validation (Markland & Tobin, 2004). Consequently, the BREQ-2 was run without the Amotivation subscale and the 4 remaining subscales and produced a model that demonstrated very good fit,  $\chi^2(4) = 2.71, p = .257$ ; RMSEA = .041 (90% Confidence interval .00 - .15); CFI = .099; SRMR = .039.

CFA was also used to assess the factor structure of the QoL scale. Results using all 7 subscales indicated acceptable fit,  $\chi^2(7) = 120.6, p < .01$ ; RMSEA = .120 (90% Confidence interval .11 - .22); CFI = .090; SRMR = .050.

Reliability of all scales or subscales was examined and all were deemed reliable, see Table 8. The BREQ-2 External Regulation subscale with a Cronbach's Alpha of .653 is still above .60, which is considered the acceptable cut-off point for reliability measures (Cronbach, 1951).

Table 8. Reliability of All Measures

Measure	Cronbach's Alpha ( $\alpha$ )
QoL Social	.905
QoL Spiritual	.950
QoL Emotional	.937
QoL Cognitive	.915
QoL Physical	.825
QoL ADL	.896
QoL Integrated	.943
SWLS	.918
SDS	.863
EXSE	.995
MSES	.800
BREQ-2 Amotivation	.878
BREQ-2 External Regulation	.653
BREQ-2 Introjected Regulation	.777
BREQ-2 Identified Regulation	.852
BREQ-2 Intrinsic Motivation	.936

Correlational analysis of all variables revealed a number of significant relationships (see Appendix C for the full correlation matrix). As expected both self-efficacy scales showed a significant relationship with Godin PA level (EXSE,  $r = .48$ ; MSES,  $r = .43$ ) (see Table 9). The BREQ-2 subscales of intrinsic motivation ( $r = .24$ ) and identified regulation ( $r = .40$ ) were positively correlated with Godin PA level (see Table 10). SWLS was significantly positively correlated to all QoL subscales with the highest correlation being between SWLS and Integrated QoL ( $r = .81$ ) (see table 11). Godin PA level had a significant relationship with Social QoL ( $r = .22$ ), Emotional QoL ( $r = .20$ ), Cognitive QoL ( $r = .22$ ), Physical QoL ( $r = .47$ ), ADL QoL ( $r = .35$ ), and Integrated QoL ( $r = .26$ ) (see table 11).

Table 9. Correlation of All Self-Efficacy Measures and PA

		1	2	3
1	EXSE	1		
2	MSES	.27**	1	
3	PA Level	.48**	.43**	1

\* significant at  $p < .05$ ; \*\* significant at  $p < .01$

Table 10. Correlation of All Self-Determination Measures and PA

		1	2	3	4	5	6	7
1	SDS	1						
2	Amotivation	-.37**	1					
3	External	-.21**	.33**	1				
4	Introjected	-.13	-.18**	.28**	1			
5	Identified	.24**	-.62**	-.16*	.45**	1		
6	Intrinsic	.59**	-.26**	-.03	-.11	.18*	1	
7	PA Level	.21**	-.28**	-.19**	.12	.40**	.24**	1

\* significant at  $p < .05$ ; \*\* significant at  $p < .01$

Table 11. Correlation of All QoL Measures and PA

		1	2	3	4	5	6	7	8	9
1	PA Level	1								
2	Social QoL	.22**	1							
3	Spiritual QoL	.04	.50**	1						
4	Emotional QoL	.20**	.75**	.53**	1					
5	Cognitive QoL	.22**	.53**	.34**	.54**	1				
6	Physical QoL	.47**	.53**	.25**	.50**	.49**	1			
7	ADL QoL	.35**	.51**	.26**	.49**	.43**	.69**	1		
8	Integrated QoL	.26**	.80**	.44**	.88**	.56**	.63**	.65**	1	
9	SWLS	.31**	.72**	.38**	.72**	.48**	.61**	.64**	.81**	1

\* significant at  $p < .05$ ; \*\* significant at  $p < .01$

Due to the high multicollinearity among some of the subscale variables, steps were taken to eliminate variables that were not contributing to the relationships of interest. Previous research (Gill et al., 2015) indicates that SWLS is a reflection of overall

quality of life and in conjunction with the high correlation between it and the integrated QoL subscale ( $r = .81$ ), removal from future analyses was warranted.

Two sets of multiple regression analyses were performed to examine the relative contribution of variables. The self-efficacy variables (EXSE and MSES) and all self-determination variables (BREQ-2 scales of Amotivation, Extrinsic Regulation, Introjected Regulation, Identified Regulation, Intrinsic Motivation; and the SDS) were examined in relation to PA to determine if some variables could be removed prior to path analysis. A multiple regression of the EXSE and MSES as predictors of PA resulted in an  $R^2 = .26$   $F(2, 212) = 37.46$ ,  $p < .001$ . Examination of the Beta weights of this regression indicated that the MSES contributed very little above the contribution of the EXSE (see table 12). This was confirmed by simple regression on each variable, when regressed on PA, EXSE resulted in an  $R^2 = .23$   $F(1, 213) = 62.46$ ,  $p < .001$  and MSES resulted in an  $R^2 = .09$   $F(1, 213) = 23.18$ ,  $p < .001$ . The addition of the MSES, although statistically significant, appears to be practically unimportant as it adds very little to the  $R^2$  change, therefore path analyses use only the EXSE.

The multiple regression model with all five predictors BREQ-2 scores as predictors of PA produced  $R^2 = .203$ ,  $F(5, 209) = 10.64$ ,  $p < .001$ . The Identified Regulation and Intrinsic Motivation scales had significant positive regression weights and the External Regulation scale had a significant negative regression weight (see Table 13). The Amotivation and Introjected Regulation scales did not contribute to the multiple regression model and were removed. The revised model produced  $R^2 = .201$   $F(3, 211) = 17.70$ ,  $p < .001$ . The SDS measure was then added to this model ( $R^2 = .201$   $F(4, 210) =$

13.21,  $p < .001$ ). The SDS score did not contribute significantly and was not included in path analyses.

*Table 12. Standardized Regression Coefficients of Self-Efficacy Variables*

	Beta	<i>t</i>	<i>p</i> value
EXSE	.345	4.773	.001
MSSE	.227	3.140	.002

F 37.458 (2, 212);  $R^2$  change = .261

*Table 13. Standardized Regression Coefficients of BREQ-2 Variables*

	Beta	<i>t</i>	<i>p</i> value
Amotivation	.049	.579	.563
External Regulation	-.149	-2.090	.038
Introjected Regulation	.033	.422	.674
Identified Regulation	.356	3.989	.001
Intrinsic Motivation	.184	2.791	.006
SDS	.017	.206	.837

F 8.835 (6,208);  $R^2$  change = .203

### **Main Analyses**

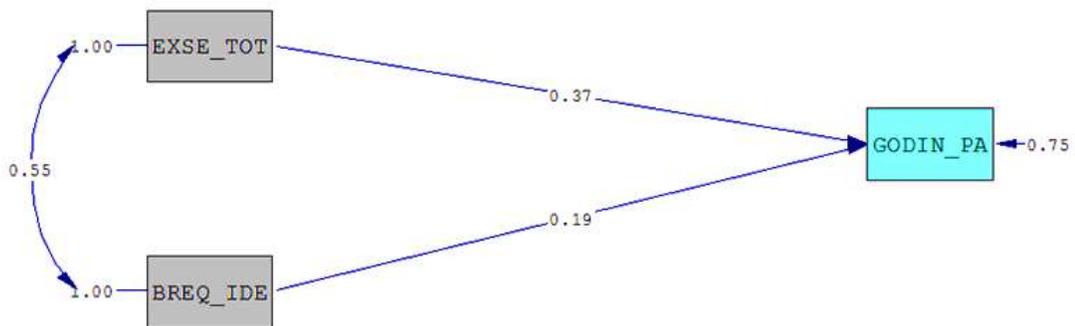
Prior to performing the main analyses, it was important for the preliminary analyses to remove extraneous variables and confirm factor structure of the measures. Accuracy of analysis depends on good factor structure of measures and variables that are not highly related but contribute to the relationships being examined (Kline, 2011). Once completed, the main research questions could be examined. Research question one explored the relationship between self-determined motivation, self-efficacy for PA, and PA levels in people with MS. Based on preliminary analysis the extraneous self-efficacy scale (MSES) and overall self-determination scale (SDS) were removed from the

analyses. Preliminary analysis also led to the removal of Amotivation and Introjected Regulation from the analysis. The path model with EXSE, BREQ-2 External Regulation, BREQ-2 Identified Regulation, and BREQ-2 Intrinsic motivation was examined. Because the four exogenous variables (EXSE, BREQ-2 External Regulation, BREQ-2 Identified Regulation, and BRE-2 Intrinsic motivation) were predicting the single endogenous variable (PA) the model fit was just identified ( $df = 0$ ) and therefore all fit indices indicated perfect fit. In this case, the parameter estimates are examined to determine if all exogenous variables have significant direct effects on the endogenous variable. Respecification of a model must be done with theoretical consideration to avoid simply capitalizing on chance (Kline, 2011). If removal of parameters and the resulting model do not make theoretical sense, statistical significance is unimportant. Path analysis relies on firm theoretical background to support the model otherwise it is possible that statistical chance is driving results (Kline, 2011). External Regulation and Intrinsic Motivation did not have significant effects and with no theoretical justification for keeping them, they were removed from the model. See Table 14 for path coefficients, standardized estimates, and significance. In the model with the remaining exogenous variables (EXSE and Identified Regulation), both had significant direct effects on PA and this model was retained. See Table 14 and Figure 10.

Table 14. Parameter Estimates for Self-Efficacy, Self-Determination and PA

Parameter	Unstandardized	SE	Standardized
<b>Model 1</b>			
EXSE	.207*	.045	.330
External Regulation	-3.010	1.759	-.101
Identified Regulation	4.155*	1.622	.179
Intrinsic Motivation	3.214	1.863	.105
<b>Model 2</b>			
EXSE	.232*	.044	.370
Identified Regulation	4.457*	1.637	.192

\* Significant at  $p < .05$



EXSE\_TOT = Total EXSE score; BREQ\_IDE = Identified Regulation; GODIN\_PA = PA Level

Figure 10. Final Path Diagram of EXSE, Identified Regulation, and PA

Research question two examines the relationship between PA participation and quality of life. The expectation is that individuals with MS who are more physically active have higher perceived quality of life. The research question is explored first with overall quality of life (using the QoL Integrated scale) and then with quality of life as a multi-dimensional construct (using the QoL scales of social, spiritual, emotional, cognitive, physical, and ADL). For the first part of the question, the regression analysis

showed a significant positive relationship,  $R^2 = .224$   $F(1, 213) = 20.314$ ,  $p < .001$ . The second part of the research explored the relationship between PA and the QoL subscales. Various renditions of the paths between PA and the QoL subscales all demonstrated poor fit (see Table 15), most likely due to the high multicollinearity among the scales. Recent research supports using the QoL Integrated scale as an overall measure of QoL, with the other subscales loading onto the Integrated scale (Gill et al., 2015). For this reason the relationship of the QoL subscales as predictors of Integrated QoL was examined. The first model, using all QoL subscales (social, spiritual, emotional, cognitive, physical, ADL) as exogenous variables and QoL Integrated as the endogenous variable, demonstrated that all parameters except QoL Cognitive showed significant direct effects. The model was run again without the QoL Cognitive variable and all parameters were significant predictors of Integrated QoL (figure 11). See Table 16 for all path coefficients, standardized estimates, and significance for the modified model.

*Table 15. Fit Indices of the Main Models Testing PA and QoL Scales*

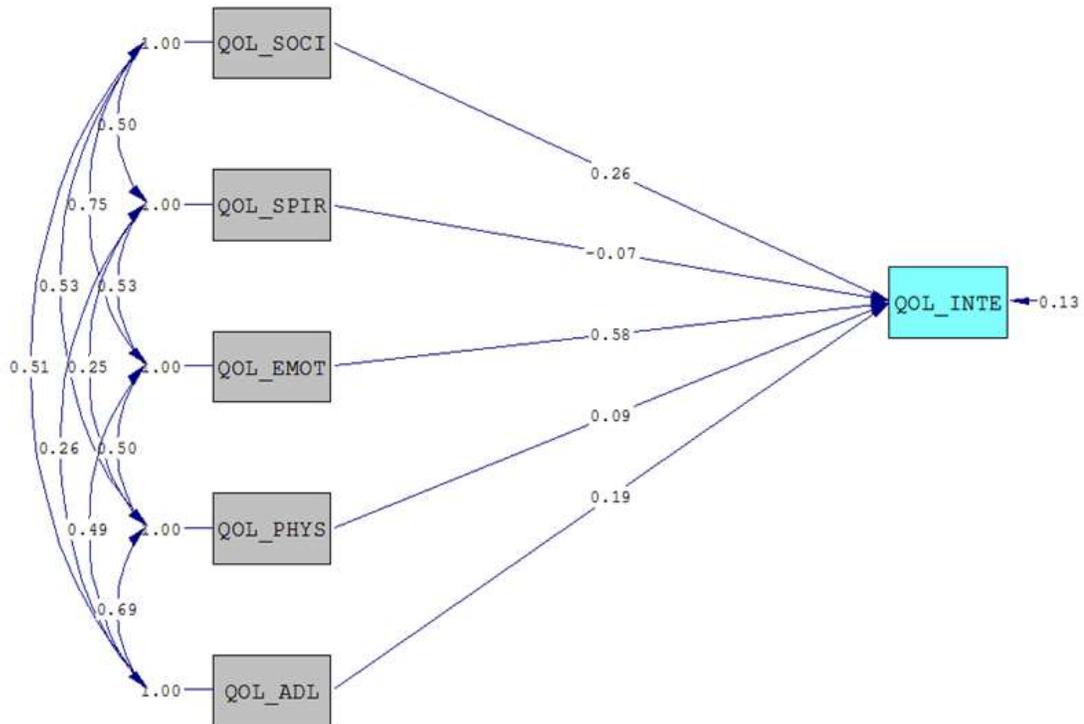
	<b>Model 1</b>	<b>Model 2</b>	<b>Model 3</b>	<b>Model 4</b>
$\chi^2(p=)$	953.79 (p<.001)	242.69 (p<.001)	456.26 (p<.001)	291.39 (p<.001)
<i>df</i>	21	3	11	7
<b>RMSEA</b>	.455	.610	.434	.435
<b>CFI</b>	.113	.280	.542	.675
<b>SRMR</b>	.382	.292	.389	.265

*Model 1: PA and all QoL scales; Model 2: PA and QoL Physical, ADL, Integrated, Model 3: PA, all QoL subscales, QoL subscales and QoL Integrated; Model 4: PA as predictor of QoL Physical, ADL, Emotional, Social and subscales as predictors of QoL Integrated. Other models were also tested but these produced the best fit. All are poorly fit models.*

Table 16. Parameter Estimates for QoL Subscales and QoL Integrated

Parameter	Unstandardized	SE	Standardized
<b>Model 1</b>			
Social	.213*	.034	.255
Spiritual	-.050*	.023	-.066
Emotional	.454*	.032	.579
Cognitive	.003	.026	.003
Physical	.076*	.031	.091
ADL	.225*	.042	.191
<b>Model 2</b>			
Social	.213*	.034	.256
Spiritual	-.050*	.023	-.066
Emotional	.455*	.032	.579
Physical	.077*	.030	.092
ADL	.225*	.042	.191

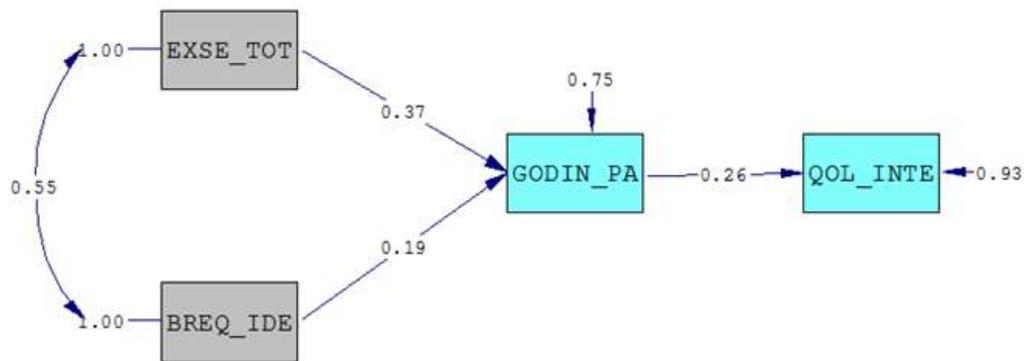
\* Significant at  $p < .05$



*QOL\_SOC = Social QoL; QOL\_SPIR = Spiritual QoL; QOL\_EMOT = Emotional QoL; QOL\_PHYS = Physical QoL; QOL\_ADL = Functional/ADL QoL; QOL\_INTE = Integrated QoL*

Figure 11. Path Diagram of QoL Subscale Relationship to QoL Integrated

The goal of this project was to combine research questions 1 and 2 and examine a model of the relationships among self-efficacy for PA, self-determined motivation for PA, PA participation, and quality of life. Based on the resulting models for both halves of the proposed overall model, the main model was tested using path analysis. The model included EXSE and BREQ Identified, PA, and QoL integrated (see figure 12). This model resulted in poor to marginal fit,  $\chi^2(2) = 8.65$ ; RMSEA = .124; SRMR = .06, CFI = .958.



*EXSE\_TOT = Total EXSE score; BREQ\_IDE = Identified Regulation; GODIN\_PA = PA Level; QOL\_INTE = Integrated QoL*

*Figure 12. Path Model of Original Proposed Overall Relationships*

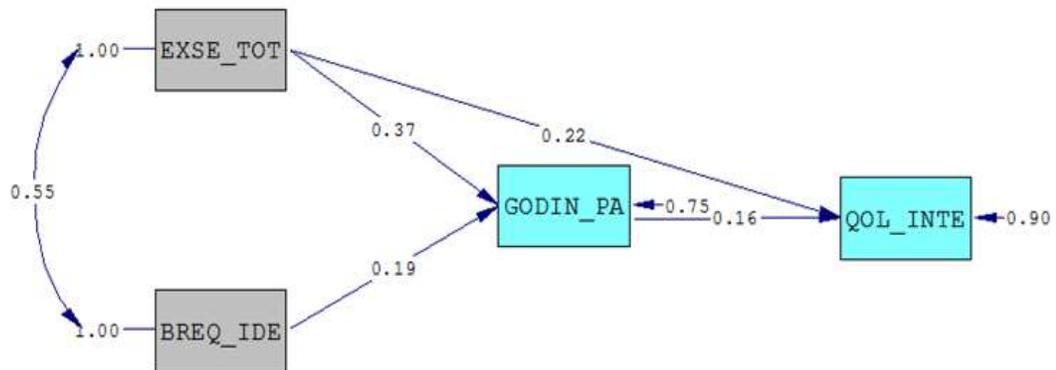
Although not included in the original overall model, there is evidence that self-efficacy directly influences quality of life in individuals with MS (Motl & McAuley, 2009); and although there is no research on the relationship between self-determination and quality of life, self-determination and self-efficacy are related constructs (Sweet et al., 2012). Therefore, the relationship between self-efficacy and quality of life, and the relationships between self-determination and quality of life were independently examined

to improve model fit. Two respecified path models were examined, one included the direct path from EXSE to QoL Integrated, and the other a direct path from BREQ Identified to QoL Integrated. Both models demonstrated good fit, see table 17. Based on previous research that supports self-efficacy as a determinant of quality of life (Motl & McAuley, 2009), and modification indices from the original model indicating an addition of a path from EXSE to Identified QoL would decrease  $\chi^2_D(1)$  by 8.4, model 2 was retained (table 17; figure 13). The mediating effect of PA between EXSE and QoL Integrated was examined using Sobel Test of Mediation (“Interactive Mediation Tests,” n.d.; Sobel, 1982). Results indicated a significant mediating effect ( $t = 1.977$ ;  $p < .05$ ).

*Table 17. Fit Indices for the Overall Model*

	<b>Model 1</b>	<b>Model 2</b>	<b>Model 3</b>
$\chi^2(p=)$	8.65 (p=.013)	.02 (p=.867)	6.56 (p=.010)
<i>df</i>	2	1	1
<i>RMSEA</i>	.124	.000	.161
<i>CFI</i>	.958	1.0	.965
<i>SRMR</i>	.060	.002	.041

*Model 1: Original model of EXSE, BREQ Identified  $\rightarrow$  PA  $\rightarrow$  QoL; Model 2: Added direct effect from EXSE to QoL; Model 3: Added a direct effect from BREQ Identified to QoL.*



*EXSE\_TOT = Total EXSE score; BREQ\_IDE = Identified Regulation; GODIN\_PA = PA Level; QOL\_INTE = Integrated QoL*

*Figure 13. Final Respecified Overall Model*

Research question three explored the relation of disease step to PA participation. The first part of the question determine whether higher disease step related to lower PA participation and quality of life. Analysis of Variance was used to assess differences in PA participation between individuals reporting low-disease step (PDDS 0-3;  $n = 108$ ) and individuals reporting high disease step (PDDS 4-8;  $n = 107$ ), see Table 18 for means and SD. The cut point corresponds with the ability to walk more than 25 feet unaided and where previous research has found a distinction in PA behavior (Klaren et al., 2013). Results indicated a significant difference in PA participation between groups,  $F(1, 213) = 20.17, p < .001$ . Crosstabs using Chi-Square also reflected this,  $\chi^2 = 18.74, p < .001$ . See Table 19 and Figure 14.

Table 18. Means and SD for PDDS and PA Levels

	Mean (SD)	Godin Mean (SD)	Range
PDDS 0 – 3	1.7 (.80)	33.71 (29.40)	0 – 173
PDDS 4 – 8	5.58 (1.39)	18.65 (18.75)	0 – 102

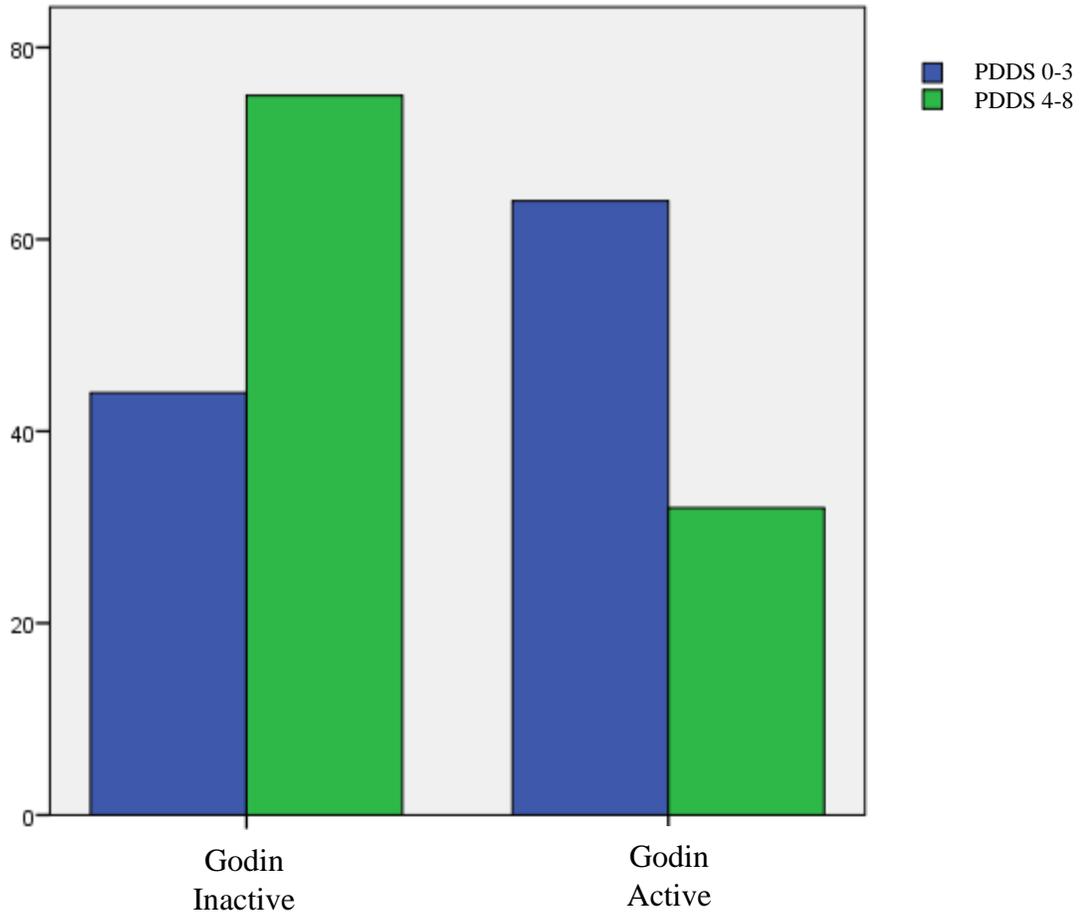


Figure 14. Relationship Between PA Level and PDDS

Table 19. Crosstabs of PA Level and PDDS

	PDDS 0-3	PDDS 4-8	Total
Godin Inactive	44	75	119
Godin Active	64	32	96
Total	108	107	215

The second part of research question 3 examined the overall model in relation to disease step to see if the model was equivalent between individuals with low or high disease step. The model was run with each of the two groups and all fit indices indicated a well-fitting model. There was no difference in the model fit. See table 19 for fit indices for both models.

*Table 20. Fit Indices for Low Disease Step and High Disease Step Models*

	<b>PDDS 0-3</b> <i>n</i> = 108	<b>PDDS 4-8</b> <i>n</i> = 107
$\chi^2(p=)$	.32 (p=.57)	2.74 (p=.39)
<i>df</i>	1	1
<b>RMSEA</b>	.001	.001
<b>CFI</b>	1.0	1.0
<b>SRMR</b>	.012	.022

### **Open-Ended Responses**

Responses to the 5 open-ended questions were first read by two separate researchers and discussed until basic themes were agreed upon, as is acceptable protocol for consensus coding (Creswell, 2013). The agreed-upon themes were in line with the research questions. Each researcher individually coded the data and then compared coding. If discrepancies existed the two discussed the statement until a code could be agreed upon (Creswell, 2013). After codes were agreed upon, individual responses were counted to determine the number that corresponded with each code. These totals are presented in tables 21 – 25.

## Describe Your Overall Quality of Life

Approximately two-thirds of participants described their quality of life as positive. “My quality of life is excellent.” Many of these participants reported the occasional bad day due to MS symptoms but still reported overall good quality of life. “In spite of physical limitations, I have a great quality of life. I am active and that's important to me. I do not drive but my husband drives me and participates in most of my activities. We go to the gym together but we each do our separate workouts.” A smaller portion of participants reported declining or poor quality of life. Those who reported poor quality of life cited MS symptoms as the cause. “I feel like I don't even have a quality of life, if I do, it is so low because I can't do the things I used to enjoy.” This sentiment was echoed by those who cited low quality of life. A summary of responses and percentage of respondents can be seen in Table 21.

*Table 21. Overall Quality Of Life of Participants*

<b>Theme/Description</b>	<b>Number of Participants</b>	<b>Percentage of total</b>
Excellent/MS has little or no impact, I am happy with how my life is	81	45.8
Good days and bad days, some limitations but mostly positive quality of life	43	24.3
Quality of life is okay but there are limitations/challenges, MS definitely impacts it, neither good nor bad	21	11.9
Quality of life is Declining, MS impacts ability and overall quality of life on regular basis	18	10.2
Quality of life is poor, there is severe MS impact, feelings of isolation, desperation	14	7.9

## How Does MS Impact Your Overall Quality of Life?

This question prompted more than one response from a number of participants. Many discussed physical and/or cognitive symptoms that limited the ability to live a normal life and the impact that had on their overall quality of life. “MS impacts me mostly from cognitive issues which all but paralyzes me at times. It is hard to communicate when you can't talk.” Others indicated that MS symptoms sometimes affected their lifestyle but did not affect their quality of life. “I don't think my MS has had an impact on my overall quality of life. I just work around the few mild symptoms that I do have.” Some respondents indicated that MS had no impact whatsoever on their lives “It doesn't”, “Minimally”, and “Not at all” were reported by this group of participants. For a summary of responses see Table 22.

*Table 22. Impact of MS on Overall Quality Of Life of Participants*

<b>Theme/Description</b>	<b>Number of Participants</b>	<b>Percentage of total*</b>
None. MS does not impact QOL	27	15.3
MS has some impact on life but positive outlook and good QOL in spite of symptoms	25	14.1
MS limits physical ability, causes fatigue, decreases QOL in some way	66	37.3
MS limits cognitive functioning, emotion strain, increased depression	18	10.1
MS limits job abilities, employment status, activities, social abilities	26	14.7
MS general limits all aspects of QOL, QOL is poor due to MS	40	22.6

*\* Percentages total more than 100% because some responses listed more than one impact; for example, many individuals cited both physical challenges and cognitive difficulties.*

### **What Motivates You to be Physically Active (If You Are)?**

This question directly asks about the motivation for PA participation. The results were in line with SDT. A small number of participants reported no motivation for PA participation (amotivation). “Nothing” and “Not very” were typical of these short responses. A number of participants reported being active for others (introjected regulation). “For my grandkids”, “My girlfriend motivates me to be healthy”, and even “My dog is a motivator. I've had her for 15 years, purposefully to keep me moving even if I was too tired.” For these individuals, they are motivated by the obligation to be healthy for the people (or animals) in their lives. A majority of participants reported some type of disease symptom control, physical benefit, health and wellness, or just generally to beat MS as the reason they were physically active (identified regulation). “I can control my cognitive symptom of MS better when I am physically active”, “I work out to keep my muscles strong. I feel that if I keep them strong, I can control them better”, and “I know swimming and strength training have made a huge impact on my MS symptoms. My gait and overall quality of life improved” are representative of the responses given. A number of participants reported participating in PA for the enjoyment of the activity (intrinsic motivation). “Because I love it” and “enjoyment” were the types of responses these individuals gave. Self-efficacy was also a theme throughout the responses. “Because I can” was a sentiment that was cited by more than one participant. A summary of responses can be found in Table 23.

Table 23. Motivation for PA Participation

Theme/Description	Number of Participants	Percentage of total*
Control physical MS symptoms	28	16
Control cognitive MS symptoms	2	1.1
Stress Management	2	1.1
Others (family, friends, health care professionals, dog)	42	24
Accomplishment, Identity, Because I can	8	4.6
Overall health, weight loss, increased strength	48	27.4
Enjoyment, feel better/good, increased mood	37	21.1
Physical appearance, to look good	7	4
Nothing, not motivated, can't do PA	23	13.1
To beat MS	11	6.3

\* Percentages total more than 100% because some responses listed more than one impact; for example, many individuals cited being active for their families and to feel better.

### How Does PA Specifically Relate to Your MS?

Many participants reported physical and/or psychological benefits and symptom management as a result of this relationship. “It helps manage stress which in turn helps manage my MS”, “The less I move the more spasticity I endure in my shoulders, arms, neck, hips and calves” and “I believe that physical activity is key to those that are living with MS. Muscle atrophy is a symptom that I experienced in my legs. I was able to slowly get strength back by being consistent over time with my workouts.” Other participants reported physical weakness or pain as a result of PA. “Fatigue, fatigue, fatigue.” And “Makes me pass out” are representative of the answers in this theme. Many of these participants reported continuing with PA because of the long-term physical benefits they saw even if the immediate result was negative. “Overall it helps but it is hard to stick it out sometimes because of the pain” and “It is more difficult to exercise because heat triggers symptoms but it is worth it” were ways that this relationship got

explained. A small number of participants reported no relationship or no desire or ability to participate in PA. For a summary of all responses see Table 24.

*Table 24. Specific Ways PA Relates to the Individual's MS*

<b>Theme/Description</b>	<b>Number of Participants</b>	<b>Percentage of total</b>
Move it or lose it, controls symptoms, disease management	53	30.6
Manage stress	2	1.1
Negative impact of PA, pain, fatigue, increased symptoms	32	18.5
Not able to be physically active	5	2.9
Increases mental state, emotional wellness, self-confidence, generally make me feel good	7	4
PA for general health and well-being, strength	11	6.4
Limited ability to do PA, Less PA than before MS	34	19.7
PA and MS related but undefined by response	15	8.7
Not related. MS does not impact PA levels	12	6.9
N/A. Not physically active, don't want to be	7	4

*\* Percentages total more than 100% because some responses listed more than one impact; for example, many individuals cited both long-term physical benefits and fatigue immediately post-exercise.*

### **How Does PA Make You Feel?**

This question prompted participants to talk about the positive and negative outcomes of PA participation. Both physical and psychological benefits were included. Many participants simply responded “good” or “excellent” in response to the question. Others elaborated on the positive feelings elicited, for example one participant said “It's always hard to get to the gym, but after my workouts I feel happy and like I achieved a big goal”. The most common negative responses were pain and fatigue related issues. “Extremely fatigued”, “HOT and sometimes that increases my fatigue”, and “Sore, tired, painful some days” were typical response from participants with this theme. Some

participants acknowledged both positive and negative outcomes. “Physical activity makes me feel great mentally but exhausted physically.” For this individual, the benefits from PA are recognized and a reason to continue participating but the negatives also contribute to the decision to participate. For a complete summary of all responses and percentages see Table 25.

*Table 25. Positive and Negative Outcomes to PA Participation*

<b>Theme/Description</b>	<b>Number of Participants</b>	<b>Percentage of total</b>
<b><i>Negative PA outcomes</i></b>		
Pain, muscle soreness, physical issues, added limitations	10	5.7
Tired, fatigue, no energy	58	33.1
Overheated, hot, heat problems	2	1.1
Anxious, depressed, sad, frustrated	6	3.4
<b><i>Positive PA outcomes</i></b>		
Positive emotional responses – confident, accomplished, enjoyment, happy, etc.	110	62.9
Cognitive improvements, thinking better	4	2.3
Physical improvements, strong, healthy	20	11.4
More energy, energized, full of life	5	2.9
<b><i>N/A</i></b>		
Explicitly stated that they cannot/do not exercise	7	4

*\* Percentages total more than 100% because some responses listed more than one impact; for example, many individuals cited both positive emotional response and fatigue.*

## CHAPTER V

### DISCUSSION

The purpose of this project was to examine the relationships among self-efficacy, self-determined motivation, PA and quality of life. First, self-efficacy, self-determined motivation for PA, and global self-determination were examined in relation to PA participation. Following that, PA was examined as a predictor of multidimensional domains of quality of life (social, spiritual, cognitive, emotional, ADL/functional, and physical) and as a predictor of overall quality of life. Finally, a path model of the relationships was developed with self-efficacy and self-determination predictors of PA and PA predicting quality of life. This model was also examined to determine whether the model was consistent for individuals at different disease levels of MS.

The first research question addressed the relationship of self-efficacy and self-determined motivation with PA. The expectation was that self-efficacy and the more internalized forms of self-determination (intrinsic motivation, identified regulation) would positively predict PA. This question was addressed first by a preliminary correlational analysis, and then through path analysis. The final path model indicated that only self-efficacy and identified regulation were predictors of PA participation. Self-efficacy is the individual's belief that they can successfully engage in an activity, in this case, PA. The relationship between self-efficacy and PA in the MS population has been seen in past research, and this result was expected (Motl & Snook, 2008). Self-efficacy

was a stronger predictor of PA behavior than identified regulation and self-efficacy had both a direct and an indirect effect (through PA) on quality of life. There is evidence that self-efficacy is an integral part of the self-determination constructs of competency and autonomy in PA settings (Sweet et al., 2012). This could explain why it was a stronger predictor of PA participation in the current model.

The more interesting part of this model is the addition of identified regulation. Identified regulation is the motivation to participate in an activity for the outcomes the activity provides (Deci & Ryan, 2004). In a physical activity scenario, these outcomes have been reported as fitness, health, and better body physique (Frederick-Recascino & Schuster-Smith, 2003). For the MS population this suggests that motivation for PA participation is partly predicted by the physical benefits in the form of disease management that participants perceived PA provided. Confirmation of this was reported by many participants in the open-ended responses. For example, “Must. Keep. Moving. If I don't use it I'll lose it”, “It (PA) keeps me limber, lessens the pain a bit and helps tremendously with balance”, “I want to keep the abilities I still have”, and “Without it (PA), I would physically be in much worse condition”. These statements reinforce the path model results. Clearly, identified regulation is important to the MS population, presumably because physical benefits in disease management are so crucial.

During the development of this model, decisions had to be made about the practical and theoretical importance of including and removing factors. If model respecification is driven only by statistics and not supported by theory it is possible to

develop a model with good fit that is a result of statistical probability (Kline, 2011). The first model of research question 1 included the BREQ-2 scales of external regulation and intrinsic motivation. These two scales did not significantly contribute to the model. Removal of the factors was done only after consideration of the overall implications. External regulation is behavior motivation that is driven by external rewards, in a PA setting an example is motivation to participate to win, as often seen in athletes (Medic, Mack, Wilson, & Starkes, 2007). A more appropriate example for this population would be because a doctor or health care professional orders PA, but this usually comes in the form of a recommendation, not an order. For individuals with a chronic, degenerative disease such as MS, the “win” does not seem a relevant motivator for PA and therefore removal was justified. Intrinsic motivation is behavior motivation driven entirely by the joy of the activity. Research suggests that in PA settings, identified regulation is a stronger predictor of PA behavior than intrinsic motivation (Teixeira et al., 2012). An examination of the open-ended responses suggested that participants were not participating in PA for the enjoyment of the activity, but instead were driven primarily by the ability to control the disease (identified regulation). The benefits derived from the activity specifically, previous research, the high path loading of identified regulation, and the open-ended responses suggest motives for PA that were not inherently intrinsic, therefore removing intrinsic motivation from the model was justified. The final model is a logically sound and statistically significant representation of the research question, demonstrating self-efficacy and identified regulation predict PA.

The second research question focused on the relationship between PA participation and quality of life. Based on previous research, the expectation was that individuals with MS who are more physically active would have higher perceived quality of life. First this relationship was explored with overall life satisfaction and results of regression analysis supported the positive relationship between PA and overall quality of life. The second part of the research question involved PA as a predictor of the individual subscales of the QoL measure (social, spiritual, emotional, cognitive, physical, and ADL). Attempts to model these relationships were unsuccessful, most likely due to high multicollinearity, and previous findings suggest that the individual subscales were predictors of the QoL Integrated scale (Gill et al., 2015). In the current study the resulting model of this relationship indicated that all but cognitive QoL predicted integrated QoL, suggesting that cognitive quality of life may be seen as a separate construct by this population. Cognitive problems are one of the few MS symptoms that are not physical in nature and are reported by a large percentage of individuals with MS (Motl, Snook, McAuley, & Gliottoni, 2006; “Symptoms & Diagnosis,” n.d.).

Open-ended responses supported PA enhancing all aspects of quality of life and MS negatively impacting it. A majority of participants reported excellent or good quality of life, with 70% of responses in these two categories. However, when asked specifically about the impact of MS on quality of life, only 15% of respondents reported that MS did not have any impact on quality of life. The remaining respondents indicated various ways that MS negatively impacted their lives including limiting physical ability and causing fatigue, limiting cognitive functioning, causing emotional strain, and increasing

depression, limiting employment status and social ability, and generally decreasing all aspects of quality of life. This is in line with previous research showing a negative impact on quality of life as a result of MS symptoms (Motl & McAuley, 2010).

Participants discussed benefits of PA participation that suggested increased overall quality of life, even when not being directly asked about the relationship of PA to quality of life. Participants also cited benefits of PA that aligned with the QoL subscales, and many participants cited more than one type of increase in quality of life that resulted from PA. For instance, one participant wrote (in response to the question about what motivates her to be physically active): “The fellowship [social quality of life]. The feeling of pride I get about myself [emotional quality of life]. The wonderful feeling of using and stretching my muscles, and hopefully weight loss [physical quality of life]!!” These results parallel the multicollinearity in the individual subscales, and lends strength to the decision to use the single integrated QoL scale for the final model.

Once both halves of the model were examined, they were combined to model the overall relationships among self-efficacy, self-determined motivation, PA, and quality of life. This model indicated that a greater portion of PA participation was explained by adding identified regulation as well as self-efficacy to the relationship, and PA in turn predicted overall quality of life. The model also demonstrated that self-efficacy has a direct effect on quality of life, meaning that individuals who feel self-efficacious perceive higher overall quality of life, regardless of PA participation.

With the overall model complete, the third research question was examined. It was expected that in line with previous findings, the more disabled the individual was, the less likely they were to participate in PA (Klaren et al., 2013). In order to explore the question of model equivalence, individuals were first divided into low-disease step and high disease step. Previous research has shown that walking mobility was the single biggest determinant of whether an individual participates in PA (Kahraman, Savci, Coskuner-Poyraz, Ozakbas, & Idiman, 2015), and the sample was divided at step 4, the point where individuals require walking assistance for mobility. As expected, results of an ANOVA confirmed that individuals in the high disease step group were less likely to participate in PA than those in the low disease step group.

The exploratory analysis to determine if the overall model held constant across disability levels indicated the models were equivalent. The path models for individual disease step groups were each the same as the overall model, demonstrating that disease step does not impact the relationships. This supports the use of the model across all MS patients. No differences between models were expected, and the result suggests the current findings and model might apply to the entire spectrum of the MS population. This also suggests that PA can be just as important to the more disabled portion of the MS population for increasing quality of life. These results suggest that future interventions should focus on the entire range of disability for the biggest impact.

## **Implications**

This research was the first of its kind to use SDT in conjunction with self-efficacy to predict PA behavior, and also examine overall quality of life using a path model with the MS population. Results indicated that the combination of self-determined motivation (identified regulation) along with self-efficacy was a stronger predictor of PA behavior than using self-efficacy by itself, as has been done previously (for examples see: Jongen et al., 2014; Motl, McAuley, Wynn, Sandroff, & Suh, 2013; Motl & Snook, 2008). In light of the extremely high level of inactivity in the MS population the current findings add another piece to the puzzle of PA motivation for this population, and that information may help develop effective interventions.

This research also adds to the growing understanding surrounding the role PA has in impacting quality of life in individuals with MS. Previous research has established the quality of life benefits seen by MS patients with PA participation (Motl & McAuley, 2010; Motl et al., 2013). This project confirmed these findings. Additionally, the open-ended responses provide greater insight into the complex relationships among PA, MS, and quality of life. Participants reported the desire and/or ability to incorporate PA into their lives because of the potential physical benefits (which resulted in quality of life benefits), but at the same time many reported short-term negative outcomes. Pain and fatigue were cited as direct results of PA for many of the participants. The dichotomy of positive and negative outcomes is important in understanding the current physical inactivity levels of MS patients. PA is beneficial to long-term quality of life, but there are

short-term negative outcomes that are sometimes experienced, discouraging PA. This needs to be considered as interventions are developed. Promoting the positive long-term quality of life outcomes of PA without acknowledging the possible short-term negative impact only provides part of the picture. Adherence to a PA program is increased through education of participants (Ransdell, 2009). Educating individuals with MS about the long-term positive outcomes (increased quality of life), in spite of the possible short-term negative outcomes, may be an effective means to increasing PA participation thus increasing quality of life.

The goal of this project was to develop an overall model to explain the relationships among self-efficacy, self-determined motivation, PA, and quality of life. The information that the model provides becomes relevant to real-world problems only when it is translated into practice. The next logical step is to develop an intervention using the roadmap that the model provides to develop a PA program for individuals with MS. Based on the results of this project, the program should focus on increasing self-efficacy and identified regulation in participants in a PA context. Longitudinal studies on self-efficacy and PA in MS patients suggest that the individual's belief that they can continue PA participation long-term is the biggest predictor of self-efficacy for PA participation (Motl, McAuley, Doerksen, Hu, & Morris, 2009). This would suggest that interventions should be designed to specifically increase self-efficacy for long-term PA. This could be done through a longitudinal program designed to teach PA behaviors throughout the duration of the program. For example, this could be a program designed to

teach MS patients how to effectively exercise within their limitations. Upon program completion, they would have the skills and knowledge to be confident in future PA.

Previous PA research has not used SDT with the MS population however, in accordance to the model, identified regulation is also a predictor of PA and therefore should be included in future interventions. Identified regulation is motivation from the benefits the activity provides the individual. For the MS population, these benefits come in the form of physical symptom control. This was echoed repeatedly in the open-ended responses, PA was a means to an end – controlling MS. Due to the nature of MS, the physical benefits gained through PA are much more drastic and immediate compared to the general population (Motl & Sandroff, 2015). Participants reported PA making a difference in daily functioning; it can be the difference between being able to care for one's self or needing assistance. Using the same hypothetical program mentioned above, identified regulation could be incorporated through tracking changes in physical ability both in the program and in day-to-day life. Logging PA improvements and how those improvements translate into real world functioning is the key to effectively incorporating SDT and specifically identified regulation into an intervention.

PA increases physical ability and this translates into physical quality of life outcomes that impact overall quality of life. Therefore, a program based on the model focusing on developing self-efficacy through guided participation and identified regulation through education should result in developing long term PA participation. This in turn should increase overall quality of life.

## **Limitations and Other Considerations**

As with all research, this study has limitations. It should be noted that these path analyses are an attempt to fit a model to data, good fit does not guarantee the model is substantively correct (Kline, 2011). An examination of integrated quality of life in the final model shows that 90% of the variance in quality of life is still not accounted for. This suggests that other variables that are not included in the model influence overall quality of life. It is important to note that quality of life is a multidimensional and complex construct that may not be easily measured with survey research (Gill et al., 2013). Without taking participants' individual needs and situations into consideration, it is extremely difficult to assess the impact that PA has on quality of life (Gill et al., 2013). This is the most probable reason for the high variance in the model.

It is important to consider that in path analysis, the direction of each path is specified as unidirectional. In real-world situations, this is not necessarily true. For example, there is research that supports a two-way relationship between self-efficacy and PA participation – the higher the person is on self-efficacy the more likely they are to participate (as the model indicates), but also the more they participate in PA the higher their self-efficacy for PA is (Bandura, 1997). It is possible that many of the paths fit this type of bidirectional theory. If that is the case, then this is less of a predictive model and more a picture of one of the many ways these relationships may occur at a given point.

Self-determination as posited by SDT, is an artificially divided trait (amotivation, external regulation, introjected regulation, identified regulation, integrated regulation, and

intrinsic motivation). The motivational continuum is divided into categories and behavioral traits are assigned to those categories. There is no room for individuals to possess characteristics that do not fit a single category. It may make more sense to have each of the levels of the continuum act like dimmer switches – where the individual possesses all of the categories and the situation dictates which categories are on “high” and which are not. If this is the case, then modeling the relationship as the present project has done is simplistic and limiting. With a multidimensional trait model such as this it would be more appropriate to do cluster type analysis.

It is also possible that the sample of individuals who responded were biased toward PA behavior. Although the recruitment flyer, email, and posted information were general in their description of the research, the stated purpose of the study (to examine PA participation and quality of life perceptions) was disclosed in IRB informed consent form and the information could have contributed to the large number of individuals ( $n = 50$ ) who stopped participating after initially clicking on the link and reading the informed consent. Additionally, even the general recruitment flyer stated the research was about “quality of life and recreational activities” and this may have been enough to turn off many participants. If those 50 individuals had drastically differing views than the sample respondents the results may be different. There is also speculation that participants who volunteer for research are inherently different than the portion of the population that does not respond (Abraham, Helms, & Presser, 2009; “Assessing the Representativeness of Public Opinion Surveys,” 2012; Smith, 2012). Nonresponse rate becomes especially

relevant when the same type of characteristics that may increase the likelihood of survey response, such as motivation, are being examined in the research.

Recruitment for this project primarily used the NMSS, regional NMSS chapters, and local support groups. Individuals with MS who are not involved in this type of peer support were not reached. It is possible that certain characteristics inherent to those individuals who are members of these types of groups are the same characteristics seen in the results. For example, depression is a well-known and often reported symptom of MS (Coyle & Hamaad, 2006). Depression is also known to limit social interactions and cause individuals to become withdrawn and isolated, which then would suggest a lower likelihood of participation in groups, social interactions, and general contact with the rest of the world (Johnson, 2000). Depression is only one example of the many confounds that may limit an individual's participation in this research because of recruitment.

### **Conclusion**

MS affects the lives of 2.1 million people worldwide (National Multiple Sclerosis Society, 2005). The neurological damage that occurs during disease progression can take many forms and may impact multiple aspects of the individual's physical and cognitive functioning ability. Disease management relies on effectively managing symptoms through various methods, including PA, in an effort to improve long-term prognosis, resulting in increased quality of life. PA benefits for individuals with MS are well documented and the evidence continues to grow (Motl & McAuley, 2009; Motl & Snook, 2008). In spite of this information, the MS population is largely inactive (Klaren et al.,

2013). This project was designed to examine SDT in conjunction with self-efficacy in an examination of PA. The goal of project was to understand how to increase PA participation to improve quality of life by developing a model of the relationships among self-efficacy, self-determined motivation, PA, and quality of life. This model added new information to the existing body of research surrounding PA motivation in MS patients by introducing identified regulation as a motivator for PA. The model demonstrated self-efficacy and identified regulation were predictors of PA and PA was a predictor of quality of life. Results were confirmed in the open-ended responses, with self-efficacy and self-determined motivation described as reasons individuals are physically active, and PA was cited as a means to directly and indirectly increase quality of life. These results provide promising directions for the future of PA interventions in the MS population. This model can guide future interventions to effectively promote PA in the MS population, resulting in a more physically active population, and contribute to long-term disease management and increased quality of life.

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APPENDIX A

MEASURES

**Godin Leisure Time Exercise Questionnaire (Godin)**

In this section, we would like to ask you about your current physical activity and exercise habits that you perform regularly, at least once a week. Please answer as accurately as possible.

**1.) During a typical 7-Day period (a week), how many times on the average do you do the following kinds of exercise for more than 15 minutes during your free time (write in each box the appropriate number).**

Times/week  
Minutes/session

STRENUOUS EXERCISE (HEART BEATS RAPIDLY):      \_\_\_\_\_      \_\_\_\_\_  
e.g.- running, jogging, elliptical, hockey, football, soccer,  
racquetball, basketball, cross country skiing, martial arts,  
roller skating, vigorous swimming, vigorous long  
distance bicycling

MODERATE EXERCISE (NOT EXHAUSTING):      \_\_\_\_\_      \_\_\_\_\_  
e.g.- fast walking, baseball/softball, badminton, tennis,  
volleyball, easy swimming, easy bicycling, dancing

MILD EXERCISE(MINIMAL EFFORT):      \_\_\_\_\_      \_\_\_\_\_  
e.g.-yoga, archery, fishing, bowling, golf,  
easy walking

**2.) Please list specific physical activities that you participate in regularly.**

### Quality of Life Survey – Version 2 (QoL)

This questionnaire asks how you feel about your **quality of life**, including your physical, emotional, social, spiritual and mental health and well-being. Please answer all questions. There are no right or wrong answers. Use the 1-5 scale below and *circle* the *one* number that best describes how you feel about your quality of life.

Poor      Below Average      Average      Above Average      Excellent  
           1                    2                    3                    4                    5

How would you rate the **quality** of your...

	Poor	Below Average	Average	Above Average	Excellent
1. Physical health and well-being	1	2	3	4	5
2. Personal Relationships	1	2	3	4	5
3. Peace of mind	1	2	3	4	5
4. Feeling of happiness	1	2	3	4	5
5. Ability to concentrate	1	2	3	4	5
6. Physical fitness	1	2	3	4	5
7. Overall quality of life	1	2	3	4	5
8. Ability to think	1	2	3	4	5
9. Enjoyment of life	1	2	3	4	5
10. Sense of calm and peacefulness	1	2	3	4	5
11. Ability to take care of yourself	1	2	3	4	5
12. Life in general	1	2	3	4	5
13. Intimate relationships	1	2	3	4	5
14. Prayer, meditation, or individual spiritual study	1	2	3	4	5
15. Ability to do activities of daily living	1	2	3	4	5
16. Happiness in general	1	2	3	4	5
17. Ability to initiate and maintain relationships	1	2	3	4	5

How would you rate the **quality** of your...

	Poor	Below Average	Average	Above Average	Excellent
18. Spiritual growth	1	2	3	4	5
19. Sense of NOT feeling sad, blue, or depressed	1	2	3	4	5
20. Ability to solve problems	1	2	3	4	5
21. Emotional relationships with others	1	2	3	4	5

22. Spiritual beliefs	1	2	3	4	5
23. Sense of NOT feeling worried, tense or anxious	1	2	3	4	5
24. Body shape	1	2	3	4	5
25. Spiritual life	1	2	3	4	5
26. Memory	1	2	3	4	5
27. Bodily appearance	1	2	3	4	5
28. Social relationships	1	2	3	4	5
29. Faith	1	2	3	4	5
30. Ability to continue learning	1	2	3	4	5
31. Level of Physical activity	1	2	3	4	5
32. Ability to get around	1	2	3	4	5

**QoL Survey Scales and Related Items:**

*Social* (5 items): Q2 + Q13 + Q17 + Q21 + Q28

*Spiritual* (5 items): Q14 + Q18 + Q22 + Q25 + Q29

*Emotional* (5 items): Q3 + Q4 + Q10 + Q19 + Q23

*Cognitive* (5 items): Q5 + Q8 + Q20 + Q26 + Q30

*Physical* (5 items): Q1 + Q6 + Q24 + Q27 + Q31

*ADL/functional* (3 items): Q11 + Q15 + Q32

*Integrated* (4 items): Q7 + Q9 + Q12 + Q16

### Satisfaction with Life Scale (SWLS)

Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

- 7 - Strongly agree
- 6 - Agree
- 5 - Slightly agree
- 4 - Neither agree nor disagree
- 3 - Slightly disagree
- 2 - Disagree
- 1 - Strongly disagree

\_\_\_\_\_ In most ways my life is close to my ideal.

\_\_\_\_\_ The conditions of my life are excellent.

\_\_\_\_\_ I am satisfied with my life.

\_\_\_\_\_ So far I have gotten the important things I want in life.

\_\_\_\_\_ If I could live my life over, I would change almost nothing.

- 31 - 35 Extremely satisfied
- 26 - 30 Satisfied
- 21 - 25 Slightly satisfied
- 20 Neutral
- 15 - 19 Slightly dissatisfied
- 10 - 14 Dissatisfied
- 5 - 9 Extremely dissatisfied

## The Self-Determination Scale (SDS)

Instructions: Please read the pairs of statements, one pair at a time, and think about which statement within the pair seems more true to you at this point in your life. Indicate the degree to which statement A feels true, relative to the degree that Statement B feels true, on the 5-point scale shown after each pair of statements. If statement A feels completely true and statement B feels completely untrue, the appropriate response would be 1. If the two statements are equally true, the appropriate response would be a 3. If only statement B feels true  
And so on.

1.

- A. I always feel like I choose the things I do.
- B. I sometimes feel that it's not really me choosing the things I do.

**Only A feels true**    1    2    3    4    5    **Only B feels true**

2.

- A. My emotions sometimes seem alien to me.
- B. My emotions always seem to belong to me.

**Only A feels true**    1    2    3    4    5    **Only B feels true**

3.

- A. I choose to do what I have to do.
- B. I do what I have to, but I don't feel like it is really my choice.

**Only A feels true**    1    2    3    4    5    **Only B feels true**

4.

- A. I feel that I am rarely myself.
- B. I feel like I am always completely myself.

**Only A feels true**    1    2    3    4    5    **Only B feels true**

5.

- A. I do what I do because it interests me.
- B. I do what I do because I have to.

**Only A feels true**    1    2    3    4    5    **Only B feels true**

6.  
A. When I accomplish something, I often feel it wasn't really me who did it.  
B. When I accomplish something, I always feel it's me who did it.

**Only A feels true**    1    2    3    4    5    **Only B feels true**

7.  
A. I am free to do whatever I decide to do.  
B. What I do is often not what I'd choose to do.

**Only A feels true**    1    2    3    4    5    **Only B feels true**

8.  
A. My body sometimes feels like a stranger to me.  
B. My body always feels like me.

**Only A feels true**    1    2    3    4    5    **Only B feels true**

9.  
A. I feel pretty free to do whatever I choose to.  
B. I often do things that I don't choose to do.

**Only A feels true**    1    2    3    4    5    **Only B feels true**

10.  
A. Sometimes I look into the mirror and see a stranger.  
B. When I look into the mirror I see myself.

**Only A feels true**    1    2    3    4    5    **Only B feels true**

**Scoring Information for the SDS.** First, items 1, 3, 5, 7, 9 need to be reverse scored so that higher scores on every item will indicate a higher level of self-determination. To reverse score an item, subtract the item response from 6 and use that as the item score. Then, calculate the scores for the Awareness of Self subscale and the Perceived Choice subscale by averaging the item scores for the 5 items within each subscale. The subscales are:

Awareness of Self: 2, 4, 6, 8, 10

Perceived Choice: 1, 3, 5, 7, 9

## EXERCISE REGULATIONS QUESTIONNAIRE (BREQ-2)

### *WHY DO YOU ENGAGE IN EXERCISE?*

We are interested in the reasons underlying peoples' decisions to engage, or not engage in physical exercise. Using the scale below, please indicate to what extent each of the following items is true for you. Please note that there are no right or wrong answers and no trick questions. We simply want to know how you personally feel about exercise. Your responses will be held in confidence and only used for our research purposes.

<b>true</b>	<b>Not true</b>	<b>Sometimes</b>	<b>Very</b>	
	<b>for me</b>	<b>true for me</b>	<b>for me</b>	
1 I exercise because other people say I should	0	1	2	3 4
2 I feel guilty when I don't exercise	0	1	2	3 4
3 I value the benefits of exercise	0	1	2	3 4
4 I exercise because it's fun	0	1	2	3 4
5 I don't see why I should have to exercise	0	1	2	3 4
6 I take part in exercise because my friends/family/partner say I should	0	1	2	3 4
7 I feel ashamed when I miss an exercise session	0	1	2	3 4
8 It's important to me to exercise regularly	0	1	2	3 4
9 I can't see why I should bother exercising	0	1	2	3 4
10 I enjoy my exercise sessions	0	1	2	3 4
11 I exercise because others will not be pleased with me if I don't	0	1	2	3 4
12 I don't see the point in exercising	0	1	2	3 4
13 I feel like a failure when I haven't	0	1	2	3 4

exercised in a while

14	I think it is important to make the effort to exercise regularly	0	1	2	3	4
15	I find exercise a pleasurable activity	0	1	2	3	4
16	I feel under pressure from my friends/family to exercise	0	1	2	3	4
17	I get restless if I don't exercise regularly	0	1	2	3	4
18	I get pleasure and satisfaction from participating in exercise	0	1	2	3	4
19	I think exercising is a waste of time	0	1	2	3	4

**Thank you for taking part in our research**

### Patient Determined Disease Step (PDDS)

Please read the choices listed below and choose the one that best describes your own situation. This scale focuses mainly on how well you walk. Not everyone will find a description that reflects their condition exactly, but please mark the one category that describes your situation the closest.

- 0 Normal:** I may have some mild symptoms, mostly sensory due to MS but they do not limit my activity. If I do have an attack, I return to normal when the attack has passed.
- 1 Mild Disability:** I have some noticeable symptoms from my MS but they are minor and have only a small effect on my lifestyle.
- 2 Moderate Disability:** I don't have any limitations in my walking ability. However, I do have significant problems due to MS that limit daily activities in other ways.
- 3 Gait Disability:** MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need a cane or other assistance to walk, but I might need some assistance during an attack.
- 4 Early Cane:** I use a cane or a single crutch or some other form of support (such as touching a wall or leaning on someone's arm) for walking all the time or part of the time, especially when walking outside. I think I can walk 25 feet in 20 seconds without a cane or crutch. I always need some assistance (cane or crutch) if I want to walk as far as 3 blocks.
- 5 Late Cane:** To be able to walk 25 feet, I have to have a cane, crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances.
- 6 Bilateral Support:** To be able to walk as far as 25 feet I must have 2 canes or crutches or a walker. I may use a scooter or wheelchair for longer distances.
- 7 Wheelchair / Scooter:** My main form of mobility is a wheelchair. I may be able to stand and/or take one or two steps, but I can't walk 25 feet, even with crutches or a walker.
- 8 Bedridden:** Unable to sit in a wheelchair for more than one hour.

### Exercise Self-Efficacy Scale (EXSE)

The items listed below are designed to assess your beliefs in your ability to continue exercising on a three times per week basis at moderate intensities (upper end of your perceived exertion range), for **40+** minutes per session in the future. Using the scales listed below please indicate how confident you are that you will be able to continue to exercise in the future.

For example, if you have complete confidence that you could exercise three times per week at moderate intensity for **40+** minutes for the next four weeks without quitting, you would **circle 100%**. However, if you had no confidence at all that you could exercise at your exercise prescription for the next four weeks without quitting, (that is, confident you would not exercise), you would **circle 0%**.

Please remember to answer honestly and accurately. There are no right or wrong answers.

**Mark your answer by circling a %:**

0%      10%   20%   30%   40%   50%   60%   70%   80%   90%  
100%

NOT AT ALL  
CONFIDENT

MODERATELY  
CONFIDENT

HIGHLY  
CONFIDENT

---

1. I am able to continue to exercise three times per week at moderate intensity, for 40+ minutes without quitting for the NEXT WEEK

0%      10%   20%   30%   40%   50%   60%   70%   80%   90%  
100%

2. I am able to continue to exercise three times per week at moderate intensity, for 40+ minutes without quitting for the NEXT TWO WEEKS

0%      10%   20%   30%   40%   50%   60%   70%   80%   90%  
100%

3. I am able to continue to exercise three times per week at moderate intensity, for 40+ minutes without quitting for the NEXT THREE WEEKS

0%      10% 20% 30% 40% 50% 60% 70% 80% 90%  
100%

4. I am able to continue to exercise three times per week at moderate intensity, for 40+ minutes without quitting for the NEXT FOUR WEEKS

0%      10% 20% 30% 40% 50% 60% 70% 80% 90%  
100%

5. I am able to continue to exercise three times per week at moderate intensity, for 40+ minutes without quitting for the NEXT FIVE WEEKS

0%      10% 20% 30% 40% 50% 60% 70% 80% 90%  
100%

6. I am able to continue to exercise three times per week at moderate intensity, for 40+ minutes without quitting for the NEXT SIX WEEKS

0%      10% 20% 30% 40% 50% 60% 70% 80% 90%  
100%

7. I am able to continue to exercise three times per week at moderate intensity, for 40+ minutes without quitting for the NEXT SEVEN WEEKS

0%      10% 20% 30% 40% 50% 60% 70% 80% 90%  
100%

8. I am able to continue to exercise three times per week at moderate intensity, for 40+ minutes without quitting for the NEXT EIGHT WEEKS

0%      10%   20%   30%   40%   50%   60%   70%   80%   90%  
100%

\*\*\*\*\*

*Scoring: Sum all items and divide by 8*

## Markus Self-Efficacy for Physical Activity

Choose the number to indicate how confident you are that you could be physically active in each of the following situations

**Scale:**

- 1 = not at all confident
- 2 = slightly confident
- 3 = moderately confident
- 4 = very confident
- 5 = extremely confident

<b>I am confident I can participate in regular exercise when:</b>					
I am tired.	1	2	3	4	5
I am in a bad mood.	1	2	3	4	5
I feel I don't have the time.	1	2	3	4	5
I am on vacation.	1	2	3	4	5
It is raining or snowing.	1	2	3	4	5

Scoring: Add all score and divide by 5. Total self-efficacy for PA score ranges from 5 to 25.

## Basic Demographics Questions

1. How old are you (in years)?
2. What gender do you identify with? (male/female)
3. What race/ethnicity do you identify with?
  - a. White
  - b. African American
  - c. American Indian
  - d. Hispanic
  - e. Asian/Pacific Islander
  - f. Other
  - g. Prefer not to answer
4. What is the highest level of education you have completed?
  - a. High school
  - b. Some college
  - c. College degree
  - d. Graduate degree
  - e. Other
5. Are you employed? (yes/no)
  - a. If so, what is your current occupation?
6. How long ago were you diagnosed with MS? (in years)
7. How often do you experience acute MS flare-ups that impact your daily life?
  - a. 1 or less
  - b. 2-3 times per year
  - c. 4-6 times per year
  - d. 6-8 times per year
  - e. 9 or more times per year
8. When was your last MS flare-up?
  - a. Less than 1 month ago
  - b. 1-2 months ago
  - c. 3-4 months ago
  - d. 5-6 months ago
  - e. 7-9 months ago
  - f. 10-12 months ago
  - g. More than 12 months ago
9. What are the most common MS symptoms that you experience?
10. Are you physically active? (yes/no)

11. Were you physically active before you were diagnosed with MS? (yes/no)
12. What types of physical activity do you participate in?

### **Open-ended Questions**

1. What are the most common MS symptoms you experience?
2. What type of recreational activities do you participate in/enjoy?
3. Describe your overall quality of life.
4. How does MS impact your quality of life?
5. What motivates you to be physically active (if you are)?
6. How does PA make you feel?
7. How does PA specifically relate to your MS?
8. How does PA impact your overall quality of life?

APPENDIX B  
RECRUITMENT MATERIALS

**Email recruiting script**

Hello.

My name is Kimberly Fasczewski and I am a doctoral candidate in the Kinesiology department at The University of NC at Greensboro. My specific research interests explore quality of life in individuals with multiple sclerosis (MS). My dissertation research examines some of the factors that may impact quality of life in people with MS such as recreational activities and physical activity participation.

Participants for this research need to be between the ages of 18 and 65 and have been diagnosed with MS at least one year ago. There are no other requirements.

As a participant, you will be asked to fill out an anonymous online survey that will take less than 20 minutes of your time and can be done at your convenience. The survey will ask about your thoughts, behaviors, and motives for activities you may participate in as well as how you rate your quality of life and satisfaction with life. If at any time during the online survey you no longer wish to participate you are welcome to stop. You have no obligation to continue. The results you have already submitted at that point may still be used.

There is no compensation for participation but this research is designed to help advance knowledge and treatment protocols for MS. Your participation can help that.

Thank you for your time. Please feel free to contact myself or my advisor if you have any questions or concerns.

Survey link: [https://uncg.qualtrics.com.SE/?SID=SV\\_3JH5TjvAH6TCLPf](https://uncg.qualtrics.com.SE/?SID=SV_3JH5TjvAH6TCLPf)

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Faculty Advisor  
Diane Gill, PhD  
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Department of Kinesiology, The University of North Carolina at Greensboro

## Online Recruitment Flyer

### **MULTIPLE SCLEROSIS AND QUALITY OF LIFE RESEARCH STUDY**

Do you have MS?  
Are you willing to take 20 minutes to help MS research?

*A new study from The University of North Carolina at Greensboro is exploring quality of life in MS patients by looking at thoughts, behaviors, and motives for the activities individuals with MS participate in. Participants with MS from ages 18-65 are needed.*

The anonymous survey can be found at:

[https://uncg.qualtrics.com/SE/?SID=SV\\_3JH5TjvAH6TCLPf](https://uncg.qualtrics.com/SE/?SID=SV_3JH5TjvAH6TCLPf)

Please contact Kimberly Fasczewski with any questions at: [kfascze@uncg.edu](mailto:kfascze@uncg.edu); (423)-400-3009

APPENDIX C  
ADDITIONAL TABLES

*Table 26. Correlations for All Measures*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1 EXSE	1															
2 MSES	.58**	1														
3 SDS	.27**	.32**	1													
4 Amotivation	-.38**	-.46**	-.37**	1												
5 External	-.16*	-.19**	-.21**	.33**	1											
6 Introjected	.13	.12	-.13	-.18**	.28**	1										
7 Identified	.55**	.56**	.24**	-.62**	-.16*	.45**	1									
8 Intrinsic	.29**	.37**	.59**	-.26**	-.03	-.11	.18*	1								
9 PA Level	.48**	.43**	.21**	-.28**	-.19**	.12	.40**	.24**	1							
10 Social QoL	.28**	.38**	.57**	-.35**	-.10	.01	.29**	.76**	.22**	1						
11 Spiritual QoL	.04	.19**	.34**	-.16**	.04	-.09	.10	.68**	.04	.50**	1					
12 Emotional QoL	.24*	.32**	.59**	-.23**	-.10	-.19**	.13	.90**	.20**	.75**	.53**	1				
13 Cognitive QoL	.28**	.39**	.45**	-.25**	-.02	.01	.36**	.55**	.22**	.53**	.34**	.54**	1			
14 Physical QoL	.57**	.58**	.45**	-.39**	-.12	.07	.46**	.59**	.47**	.53**	.25**	.50**	.49**	1		
15 ADL QoL	.40**	.48**	.46**	-.28**	-.08	.02	.21**	.69**	.35**	.51**	.26**	.49**	.43**	.69**	1	
16 Integrated QoL	.29**	.37**	.65**	-.34**	-.14*	-.11	.19**	.87**	.26**	.80**	.44**	.88**	.56**	.63**	.65**	1
17 SWLS	.36**	.42**	.59**	-.30**	-.15	-.06	.23**	.74**	.31**	.72**	.38**	.72**	.48**	.61**	.64**	.81**

\* significant at  $p < .05$ ; \*\* significant at  $p < .01$