

AN ABSTRACT OF THE DISSERTATION OF

Mara B. Nery for the degree of Doctor of Philosophy in Kinesiology presented on August 15, 2016.

Title: Multiple Sclerosis and Wellness: How Self-Compassion Influences Physical Activity and Health-Related Quality of Life

Abstract approved:

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Multiple Sclerosis (MS) is an autoimmune condition that affects the central nervous system, and impacts the lives of over 400,000 individuals in the US. These individuals face unpredictable relapses of disabling conditions, are less active and experience poorer quality of life than the general population. Health professionals are challenged to find ways to increase engagement in health promoting behaviors that can improve function and overall wellness for this population. The major objective of this dissertation was to expand the literature on promoting health behaviors and wellness through self-compassion for individuals with MS. One theoretical model that has the potential to help researchers and program developers understand how to effectively improve engagement in health behaviors for individuals with MS is Reyes' model of self-compassion. The first aim of the first study was to cross-validate Reyes conceptual model of self-compassion among individuals with MS. Although the model is promising, recent studies suggest fatigue may play a unique role for individuals with MS. The second aim of the first study was to examine the utility of an alternative model, which expands upon Reyes' model. Furthermore, self-compassion has been shown to improve resilience and quality of life in the

general population. The second study aimed to understand the relationship between self-compassion, resilience and health-related quality of life for individuals with MS. Individuals (N = 259) participated in a survey measuring their perceived fatigue, self-compassion, psychological needs related to exercise, resilience, health-related quality of life, and self-reported physical activity, as well as a demographic questionnaire. Participants were predominately white (90%) females (84%), with a relapse-remitting MS course (73%), and a mean age of 48.60 (SD = 10.46). Study 1 validated the use of Reyes' conceptual model of self-compassion. However, the alternative model, which added direct paths to psychological needs and fatigue, showed improved fit over Reyes' model for this population. Results demonstrated that fatigue predicted engagement in physical activity in both models, which was expected. However, in the alternative model, fatigue significantly negatively predicted psychological needs for engaging in exercise, but showed a non-significant, weak relationship with physical activity behavior, which was unexpected. Study 2 examined the relationship between self-compassion, resilience, and health-related quality of life for individuals with MS using mediation analysis. Results from this study showed that resilience was a partial mediator between self-compassion and health-related quality of life. The results from these studies can inform future health interventions seeking to improve health-related quality of life and engagement in physical activity in this population. Both of these studies contribute to the theoretical knowledge of self-compassion, wellness, and behavior change for individuals with MS.

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Multiple Sclerosis and Wellness: How Self-Compassion Influences Physical
Activity and Health-Related Quality of Life

by

Mara B. Nery

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APPROVED:

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Dean of the Graduate School

I understand that my dissertation will become part of the permanent collection of Oregon State Universities libraries. My signature below authorizes release of my dissertation to any reader upon request.

Mara B. Nery, Author

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CONTRIBUTION OF AUTHORS

Mara B. Nery, MPH, M.S., conceptualized this project, collected data, conducted data analyses, interpreted the findings, and drafted the manuscripts.

Joonkoo Yun, Ph.D., assisted in the project conceptualization, research design, interpretation of data, and provided editorial comments and suggestions on the final draft.

Vicki Ebbeck, Ph.D., assisted in the project conceptualization, research design, and interpretation of data.

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Chapter 1: General Introduction

Multiple Sclerosis and Wellness: How self-compassion influences physical activity and health-related quality of life

Multiple Sclerosis (MS) is an autoimmune condition that affects the central nervous system, and impacts the lives of over 400,000 individuals in the US (National MS Society, 2013). Multiple Sclerosis, which is often associated with periods of relapsing symptoms, causes a wide variety of associated conditions (e.g., fatigue, thermoregulatory impairment, lack of balance, cognitive impairment, spasticity, contractures) and leads to secondary conditions (e.g., depression, obesity, cardiovascular disease) that cause individuals with MS to experience poorer health than the general population (White & Dressendorfer, 2004). As individuals experience unpredictable relapses of symptoms, develop secondary conditions and face greater disability, they have increased difficulty completing activities of daily living, which decreases functional independence and reduces their quality of life (Benito-Leo'n, Morales, Rivera-Navarro, & Mitchell, 2003; Miltenburger & Kobelt, 2002; Mitchell, Benito-Leon, Gonzales, & Rivera-Navarro, 2005). For many individuals, this leads to a cycle of degrading health and other disabling conditions, which could be otherwise prevented or mitigated by interventions that increase health behaviors such as physical activity.

Physical activity has been shown to improve mobility, cognitive function, strength and fitness, and reduce fatigue for individuals with MS, as well as help manage common MS symptoms, promote wellness, and increase participation in social activities (Dalgas, Stenager, & Ingemann-Hansen, 2008; Haskell, Lee, Pate, Powell, Blair & Franklin, 2007; Mostert & Kesselring, 2002; Motl & Gosney, 2008; Motl & Pilutti, 2012; Motl, Sandroff, & Benedict, 2011; Petajan & White, 1999). Additionally, engaging in regular physical activity has been indicated to slow the progression of some less severe cases of MS (Mostert & Kesselring, 2002; Stuifbergen, Becker, Blozis, Timmerman, & Kullberg, 2006). Yet despite the reported benefits of maintaining an active lifestyle, people with MS are

typically less active than the general population (McCullagh, Fitzgerald, Murphy, & Cooke, 2008; Motl, McAuley, & Snook, 2005). Although there may be multiple possibilities for a lack of engagement in health promoting behaviors such as physical activity, their chronic and often deteriorating condition may play a significant role. There is a need to understand the mechanisms by which we effectively promote healthy behaviors in this population to improve health outcomes and quality of life.

One behavioral theory that has the potential to help researchers and program developers understand the underlying mechanisms and improve engagement in healthy behaviors, as well as increase wellness in this population is Reyes' model of self-compassion (Reyes, 2012). Self-compassion is a central construct of this model and is defined as the desire to relieve suffering and increase acceptance of oneself (Reyes, 2012). Individuals engage in self-compassion through showing oneself kindness instead of harsh judgment and criticism; viewing personal experiences as shared by others (common humanity) rather than isolating oneself; and perceiving feelings as balanced (mindfulness) instead of over-identifying with them (Neff, 2003). Thus, self-compassion is critical when dealing with difficult life events, such as chronic disease, and when feelings of inadequacy arise, such as engaging in physical activity with a disability (Ferguson, Kowalski, Mack, & Sabiston, 2014; Neff, 2003). Reyes' model (2012) may have encouraging implications for use in populations with MS. Improving self-compassion may be one approach that has the potential to reshape how individuals with chronic conditions perceive their state of being and ability, and engage in healthy behaviors. Reyes' model shows promise for improving health behaviors. Recent research has demonstrated that for individuals with MS, fatigue may directly influence motivation and participation in physical activity (Asano, Duquette, Andersen, Lapierre, & Mayo, 2013; Motl & McAuley, 2009; Stroud, Minahan, & Sabapathy, 2009). It is important to reflect the current literature when cross validating Reyes' model for this population.

Currently, the literature on self-compassion has focused on reducing risky or negative behaviors in general populations, and encouraging results have been found (Breines & Chen, 2012; Magnus, Kowalski, & McHugh, 2010). Self-compassion has been positively related to increased motivation and effort for engaging in self-improvement activities, as well as increased belief that individuals can make beneficial changes in their own behavior (Breines & Chen, 2012; Magnus et al., 2010). Moreover, self-compassion has been linked to improved coping mechanisms related to life stressors such as chronic pain and disability, increased perceived well-being and quality of life, as well as increased engagement in health promoting behaviors such as exercising (Allen, Goldwasser, & Leary, 2012; Magnus et al., 2010). Self-compassion in the general population has been linked with increased positive affect, decreased depression and anxiety (Neff, 2009; Neff, Kirkpatrick, & Rude, 2007), and increased feelings of social connectedness (Neff et al., 2007).

The relationship has been examined between self-compassion and health promoting behaviors in the general population (Allen et al., 2012; Magnus et al., 2010; Sirois, Kitner, & Hirsch, 2014), but may not be the same among individuals with MS. Because individuals with MS face unique symptoms such as acute attacks and extreme fatigue, they may endure greater psychological challenges and negative affect (due to “suffering”) than the general population. Therefore, the overall purpose of this study was to deepen our theoretical knowledge of how self-compassion improves health-related quality of life, and engagement in health behaviors for individuals with MS.

This study aimed to expand the literature on promoting health behaviors and wellness through self-compassion for individuals with MS. Study 1 examined Reyes’ conceptual model of the transformation of suffering on psychological needs for exercise and physical activity engagement for individuals with MS, and an alternative model. Study 2 evaluated the relationship between self-compassion, resilience, and health-related quality of life for individuals with MS.

The following research questions were examined:

Study 1. Testing models of self-compassion on physical activity behavior.

Question 1: Does Reyes' model appropriately explain engagement in physical activity through fatigue, self-compassion, and self-determined motivation for individuals with MS?

Question 2: Does an alternative model better explain the relationships between fatigue, self-determined motivation, and physical activity in this population?

Study 2. Examining the mechanism by which self-compassion influences health-related quality of life.

Question 3: Does resilience partially mediate the relationship between self-compassion and health-related quality of life for individuals with MS?

Limitations

This study has several limitations:

- The majority of individuals were recruited online through social media ads and flyers. The nature of subject recruitment process makes it difficult to calculate the return rate, which may threaten the external validity of the study.
- The survey did not evaluate participants' severity of conditions, which may be a confounding factor.
- The study is cross-sectional, which does not allow for the determination of causality.

Delimitations

The delimitations of this study are:

- The population selected was adult individuals with MS who are affiliated with health advocacy and education groups, MS support groups, and exercise programs.
- The age range for participants was 18 to 65.

Assumptions

It is assumed that:

- Individuals self-reported truthfully and to the best of their knowledge on all surveys.
- Measurement tools aligned best with hypotheses of this study. For that reason, when possible, measurement tools were carefully selected which have been validated for use in populations with disabilities and/or are disability specific in language. It is assumed that these provide more accurate information for this population.

Operational Definitions

For the purposes of this study, the following terms have been operationalized:

- Health-related quality of life: A broad... sense of personal well-being, particularly as it relates to one's health" (Krahn et al., 2014).
- Psychological needs: "Represent essential conditions nourishing growth, integrity, and wellbeing" (Deci & Ryan, 1995, 2002). Self-determination theory specifies that when the needs for autonomy, competence, and relatedness are met, optimal function and growth toward positive self-determined motivation can occur (Deci & Ryan, 1995, 2002).
- Physical activity: Any movement that increases effort and heart rate, including exercise and leisure-time physical activity. Physical activity may be mild, moderate, or vigorous.

- Resilience: “Positive adaptation in the face of stress or trauma” (Luthar, Cicchetti, & Becker, 2000).
- Self-compassion: “Self-compassion involves being touched by and open to one’s own suffering, not avoiding or disconnecting from it, generating the desire to alleviate one’s suffering and to heal oneself with kindness” (Neff, 2003). Self-compassion also involves “offering nonjudgmental understanding to one’s pain, inadequacies and failures, so that one’s experience is seen as part of the larger human experience” (Neff, 2003).

Chapter 2: Manuscript 1

Improving physical activity through self-compassion for individuals with Multiple
Sclerosis: Testing a conceptual model of behavior

Abstract

The purposes of this study were to cross validate Reyes' conceptual model for individuals with MS, and examine an alternative model directly linking fatigue to psychological needs and physical activity. Participants (N = 254) completed questionnaires measuring fatigue, self-compassion, self-determined motivation, and leisure-time physical activity. Path analysis was used to examine the fit of both models, as well as identify the relationships among variables. Results indicated that the alternative model adequately fit the data, but Reyes' model did not show acceptable fit in this study. In Reyes' model, fatigue has a direct relationship with self-compassion. Self-compassion predicts self-determined motivation, which influences physical activity. The alternative model supported the direct path from fatigue to self-determined motivation, but the relationship of fatigue on physical activity was non-significant. Results from this study support the use of self-compassion to increase self-determined motivation and physical activity behavior for individuals with MS in future wellness interventions.

Introduction

Self-compassion has been receiving attention in the literature as a potential vehicle to change behavior and improve wellness. Self-compassion is an alternative way of coping with and alleviating one's own suffering by offering self-kindness and nonjudgmental understanding (Neff, 2003). Through these actions, individuals can comfort themselves in times of distress, acknowledge their pain or struggle, and know that they are not isolated in their experiences.

Recently, Reyes (2012) developed a conceptual model of self-compassion, which describes how self-compassion transforms individuals' suffering into motivation and capacity for self-care. Reyes proposes that the antecedent to self-compassion is suffering, which leads to a diminished capacity to care for oneself, decreased ability to relate to others, diminished autonomy, and decreased self-worth, which is characterized by guilt and shame. Reyes suggests that when one engages in self-compassion they increase their positive emotional response, which translates to greater motivation to try again and for self-mastery, resulting in increased autonomy, capacity for self-care or engagement in healthy behaviors, and compassion for and relatedness to others (Reyes, 2012). The Reyes model incorporates psychological needs (autonomy, related, and competence), which are the essential conditions that directly contribute to self-determined motivation for engaging in health behaviors (Deci & Ryan, 2002). Reyes suggests that when one experiences suffering they may have a triggering moment where they realize they have a choice to perceive and approach their situation differently by engaging in self-compassion (Reyes, 2012). This leads to a person desiring wellbeing and making the choices aligned with cultivating a better life for themselves. Consequently, self-compassion can lead to increasing their relatedness to others, autonomy, self-mastery, and ultimately Improving their capacity for self-care behaviors (Reyes, 2012).

Cultivating self-compassion can be beneficial when dealing with difficult life events, such as chronic disease, and when feelings of inadequacy arise such

as engaging in physical activity with a disability (Neff, 2003; Wren, Somers, Wright, Goetz, Leary, Fris et al., 2012). Wren and colleagues (2012) suggest that for individuals with debilitating chronic conditions, self-compassion may increase the ability to take a mindful attitude toward their condition, therefore being more accepting of their experience while still engaging in meaningful daily activities. One population this has potential to benefit is individuals with Multiple Sclerosis (MS).

MS is an autoimmune neurologic condition that impairs functioning by degrading nerve pathways, often is progressive in nature, and is often characterized by the occurrence of acute attacks, which are the sudden onset of conditions that impair the individual and contribute to disability (Sturm & Gurevitz, 2014). These acute attacks can vary in duration and severity, and typically result in the accumulation of mobility impairments and progressive worsening of disability. During these acute attacks, individuals are often unable to complete activities of daily living, may be unable to care for themselves, and usually experience exceptional fatigue and mobility disabilities (National MS Society, 2013). For many individuals, this leads to a cycle of secondary conditions, degrading health, and other disabling conditions, which could be otherwise prevented or mitigated by interventions that increase health behaviors such as physical activity.

Participation in regular physical activity has been shown to improve health outcomes for individuals with MS (Haskell, Lee, Pate, Powell, Blair & Franklin, 2007), through improving strength and fitness, reducing fatigue (Dalgas et al., 2008; Motl & Pilutti, 2012), managing common MS symptoms, and increasing participation in social activities (Mostert & Kesselring, 2002; Petajan & White, 1999). Yet despite the reported benefits of maintaining an active lifestyle, people with MS are typically less active than the general population (McCullagh et al., 2008; Motl et al., 2005). Although there may be multiple possibilities for a lack of engagement in physical activity, their symptoms may play significant role (Motl &

McAuley, 2009). Studies have demonstrated that fatigue is a major obstacle to engaging in exercise for individuals with MS, even when they are regular exercisers (Motl & McAuley, 2009; Stroud et al., 2009). Based on these findings, researchers have suggested investigating alternative strategies to manage symptoms such as fatigue, pain, and depression to help promote physical activity behavior for individuals with MS (Motl & McAuley, 2009; Stroud, Minahan, & Sabapathy, 2009). One method of increasing health behaviors and thereby improving health outcomes in this population may be actively engaging in self-compassion.

Understanding how self-compassion impacts health promoting behaviors, such as physical activity, can help researchers effectively utilize these mechanisms to improve health for individuals with MS. In the general population, self-compassion has been linked to increasing health promoting behaviors such as exercising (Allen et al., 2012; Magnus et al., 2010), as well as increasing positive affect, decreasing depression and anxiety (Neff, 2009; Neff, Kirkpatrick, & Rude, 2007), and increasing feelings of social connectedness (Neff et al., 2007). Because individuals with MS face extraordinary fatigue and acute attacks, they may endure greater psychological challenges and negative affect (due to “suffering”) than the general population. Therefore, self-compassion may play an important role in psychological health, as well as increasing motivation, social connectedness, and engagement in health promoting behaviors such as physical activity through an increase in self-care capacity. Reyes’ conceptual model (2012) may have encouraging implications for use in populations with MS. Improving self-compassion may be one approach that has the potential to reshape how individuals with chronic conditions perceive their state of being and ability, and engage in healthy behaviors. However, the model has not yet been tested for individuals with MS.

Furthermore, research has demonstrated that for this population, fatigue influences motivation and participation in physical activity (Motl & McAuley, 2009;

Stroud, Minahan, & Sabapathy, 2009). Although Reyes' model may increase capacity for self-care behaviors in the general population, it may not fully explain this engagement for individuals with MS. Current literature suggests that fatigue directly impacts motivation and physical activity (Asano, Duquette, Andersen, Lapierre, & Mayo, 2013; Motl & McAuley, 2009; Stroud et al., 2009).

Understanding the effects of fatigue on motivation and behavior may help practitioners develop effective programs targeted at increasing engagement in physical activity in the presence of debilitating symptoms. Therefore, we propose an alternative model that expands upon the Reyes model to examine these direct relationships. In this study, we operationalized the following concepts: (a) "suffering" as fatigue; (b) the constructs of psychological needs (autonomy, competence, and relatedness) contribute to self-determined motivation to exercise; and (c) physical activity is the directed self-care behavior.

This study aims to expand the literature on psychosocial constructs that contribute to the promotion of health behaviors for individuals with MS. The primary purpose of this study was to examine a behavior change model grounded in Reyes' conceptual model of the transformation of suffering (fatigue) through self-compassion and its effects on self-determined motivation and self-care behavior (physical activity) in this population. It is our hypothesis that self-compassion will predict engagement in physical activity through psychological needs in Reyes' model. The secondary purpose was to test an alternative model that includes direct relationships from fatigue to psychological needs and physical activity. It is our hypothesis that the alternative model will provide evidence for fatigue's impact on self-determined motivation and physical activity behavior for individuals with MS.

Methods

Participants

Two hundred and fifty-four individuals with MS were retained for final data analysis in the study. Inclusion criteria were 1) between the ages of 18-65, and

(2) having a medical diagnosis of MS. Participants may have had a medical diagnosis of any of the four types of MS (i.e., relapse-remitting, primary-progressive, secondary-progressive, and progressive-relapsing).

Participants were predominantly white (90.51%) females (84.25%) with a mean age of 48.69 (SD = 10.43). The average BMI was 28.46 (SD = 7.94; range: 17.13 – 70.31), and 59.26% (n = 143) of individuals reported being in the overweight or obese categories. Seventy-three percent of participants reported having a relapse-remitting MS course, and 18.58% were in secondary-progressive. Time since last acute attack was reported at greater than twelve months for 53.72% of individuals, followed by less than 3 months for 23.14% of individuals. Thirty-seven percent of participants were employed for wages, and 36.22% reported being unable to work due to their MS. Forty-eight percent of participants had a diagnosis of MS for ten years or less (n = 120), 29.60% had MS for 11 to 20 years (n = 74), and 22.40% had MS for between 21 and 49 years (n = 56). The majority of participants reported their health status as good, very good, or excellent (65.40%). Table 2.1 presents demographic information for this study.

Table 2.1. *Demographics of participants.*

Demographics	Percent	Frequency (n)
Sex (n = 254)		
Male	15.75%	40
Female	84.25%	214
Race (n = 253)		
White	90.51%	229
Black	1.58%	4
Native American	1.58%	4
Latino	3.95%	10
Not Listed	0.79%	2
Did not wish to disclose	1.58%	4
MS Type (n = 253)		
Relapse-remitting	72.73%	184
Secondary-progressive	18.58%	47
Primary-progressive	7.51%	19

	Progressive-Relapsing	1.19%	3
<i>Time since last acute attack (n = 242)</i>			
	Less than 3 months	23.14%	56
	3 to 6 months	10.33%	25
	7 to 9 months	4.55%	11
	10 to 12 months	8.26%	20
	Greater than 12 months	53.72%	130
<i>Health Status (n = 253)</i>			
	Poor	5.53%	14
	Fair	28.06%	71
	Good	36.15%	94
	Very good	24.11%	61
	Excellent	5.14%	13
<i>Employment (n = 254)</i>			
	Employed for wages	37.40%	95
	Self employed	3.94%	10
	Out of work greater than 12 months	6.30%	16
	Out of work less than 12 months	1.57%	4
	Homemaker	5.91%	15
	Student	1.18%	3
	Retired	7.48%	19
	Unable to work	36.22%	92
<i>BMI (n = 243)</i>			
	< 18.5	2.05%	5
	18.5 – 24.9	39.09%	95
	25.0 – 29.9	27.98%	67
	≥ 30.0	31.28%	76

Note: Differences in *n* resulted when participants did not respond to certain demographic questions.

Measures

Participants completed a survey that consisted of five questionnaires, which had a total of 70 questions: Fatigue Severity Scale (FSS), Self-Compassion Scale (SCS), Psychological Needs Satisfaction in Exercise Scale (PNSE), Leisure-Time Physical Activity Questionnaire for Individuals with Spinal Cord Injury (LTPAQ-SCI), and a demographic questionnaire, which includes questions on current health status, and information about their MS.

The FSS (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989) is 9-item measure that asks individuals to rate their agreement or disagreement on a 7-point Likert type scale with each statement as it pertains to their fatigue over the past seven days. The FSS includes questions such as, “My fatigue prevents sustained physical functioning,” and “Exercise brings on my fatigue” Total mean score was used to identify level of fatigue; higher scores represented greater fatigue. Results demonstrated good internal consistency in our sample ($\alpha = .93$), and among other studies ($\alpha = .88$) (Krupp et al., 1989).

The SCS (Neff, 2003) measured individuals’ self-compassion on 5-point Likert-type scale ranging from 1 (almost never) to 5 (almost always). This 26-item scale has three paired subscales: (1) self-kindness vs. judgment, (2) mindfulness vs. over attachment, and (3) common humanity vs. isolation. Previous research demonstrated test-retest reliability ($r = .80 - .93$) (Neff, 2003), and in our sample, the internal consistency coefficient was $\alpha = .93$. The measure includes questions such as, “When I’m going through a very hard time, I give myself the caring and tenderness I need,” and, “I’m disapproving and judgmental about my own flaws and inadequacies.” Items from judgment, over-attachment, and isolation were reverse coded, and each of the three subscale means were combined to get a total mean for self-compassion.

The 18-item PNSE was used to quantify perceived psychological needs satisfaction (Wilson, Rogers, Rogers, & Wild, 2006) with six questions in each of the three subscales: (1) perceived autonomy, (2) perceived competence, and (3) perceived relatedness. The PNSE consists of questions such as, “I feel confident in my ability to perform exercises that personally challenge me,” “I feel like I share a common bond with people who are important to me when we exercise together,” and, “I feel free to exercise in my own way.” Participants are asked to indicate how well each statement represents their feelings about exercise and physical activity using a 6-point Likert-type scale, ranging from 1 (false) to 6 (true). Means from each of the three subscales were combined to get a total

mean for the measurement tool. This measurement tool has demonstrated good internal consistencies across all subscales ($\alpha \geq .90$) (Wilson et al., 2006). In our sample, the overall internal consistency reliability was $\alpha = .94$.

Physical activity was defined as structured or unstructured exercise or activity that raises one's heart rate, and is sustained for at least ten continuous minutes. The LTPAQ-SCI (Martin Ginis, Phang, Latimer, & Arbour-Nicitopoulos, 2012) is a 3-item, one dimension, self-report measure that asks participants to recall their frequency and duration (in minutes) for engaging in mild, moderate, and vigorous intensity physical activity over the past seven days. Previous research demonstrated test-retest reliability ($r = .62 - .93$) of this measurement tool (Martin Ginis et al., 2012). Total physical activity was calculated by multiplying the frequency of each intensity category by duration of activity, and adding the total minutes from each category together.

Procedures

This study employed a convenience sample of individuals with MS. Participants were recruited from the National MS Society's local chapters and support groups, and from other MS advocacy groups and exercise programs through: email, printed flyers, social media advertisements, and in-person survey distribution.

Recruitment occurred over four months. For the email recruitment, an initial contact email was sent out to twenty-one individuals with (1) a description on the study, (2) a link to complete the online questionnaire, and (3) a deadline to complete the questionnaire. After ten days, a second reminder email was sent out with the link to the questionnaire. A final follow-up email and thank you was sent out ten days after the second contact.

Additionally, the researcher attended MS events in the area (i.e., informational events and conferences) to distribute flyers and printed surveys with postage paid return envelopes, and collect email addresses of individuals

interested in participating. Approximately 90 printed survey packets were distributed to individuals attending MS events and clinics and twelve were returned. Printed flyers with a description of the study, a link to complete the survey, and contact information of the research team were also distributed to social support groups and exercise programs.

Online advertisements were posted through social media outlets (Facebook) and to MS advocacy webpages, and sent out through e-blasts and e-newsletters. The National MS Society, the Multiple Sclerosis Foundation, and the Multiple Sclerosis Association of America all assisted with advertising the research study through their webpages and list servers. For the online social media recruitment, advertisements were posted with a brief description of the study and target population, a link to complete the survey, and contact information for the research team. Advertisements were reposted every ten days for three recruitment attempts. The university institutional review board approved all study activities, and informed consent was obtained from all participants.

Data Analyses

Demographic data (age, sex, race/ethnicity, BMI, overall health status, time since last acute attack, and duration and type of MS) were analyzed for descriptive statistics, including means and standard deviations.

A total of 339 participants were recruited. Sixteen participants were not within the 18 - 65 age range and one participant did not have a medical diagnosis of MS. After participants not meeting inclusion criteria were removed, participants who had more than 10% missing data ($n = 61$) were removed. Bennett (2001) and Rubright, Nandakumar, and Glutting (2014) recommend excluding participants with greater than ten percent missing data from the analyses, as large amounts of missing data can impact the validity of results. Lastly, self-reported physical activity data that fell beyond four standard deviations of the mean were excluded from analysis as outliers ($n = 7$). This resulted in 254 participants who were retained for the final model testing analysis. The final

participants were comprised of 3.1% (8) from printed survey packets, 7.5% (19) from email recruitment, 55.1% (140) from social media advertisement, and 34.3% (87) from flyer distribution.

Normality was checked through tests of skewness and kurtosis, and results showed that data was not normally distributed (skewness: 2.81, $p < .0001$; kurtosis = 13.95, $p < .0001$). Therefore, to obtain a more accurate relationship between endogenous and exogenous variables, the bias-corrected bootstrap resampling method was used with 1,000 random resamples and 95% bias-corrected confidence intervals were calculated (Effron, 1988; Zhu, 1997).

Correlation analyses were first conducted to identify the interrelationships among the model variables. Path analysis was used to test the models and examine the relationships between exogenous and endogenous variables.

Fit was assessed using the comparative fit index (CFI), Tucker-Lewis fit index (TFI), root mean square error of approximation (RMSEA), Chi-square (χ^2), and the standardized root mean square residual (SRMR). While acknowledging fit indices are depended on sample size, Hu and Bentler (1999) recommend a cutoff value close to .95 for fit indices (CFI & TFI). They also recommended cutoff values of .08 for SRMR and .06 for RMSEA (Hu & Bentler, 1999). For RMSEA, values less than .05 indicate a close fit, values in the range of .05 to .08 indicate a fair fit, values in the range of .08 to .10 indicate a mediocre fit, and values greater than .10 indicate a poor fit (Browne & Cudek, 1992; McCallum & Austin, 2000). Finally, Hu and Bentler (1999) concluded that in analyses with small sample sizes ($N \leq 250$), the recommended combinational rules have a slight tendency to over reject true models when data does not meet normality assumptions. Statistical analyses were conducted with STATA v.13 (StataCorp, 2013) and significance level was set at $p < 0.05$.

Results

Self-compassion was significantly and positively associated with psychological needs ($r = .44, p < .001$). Fatigue was significantly and negatively associated with self-compassion ($r = -.30, p < .001$) and psychological needs ($r = -.46, p < .001$). Physical activity was significantly negatively associated with fatigue ($r = -.14, p < .05$), and significantly positively associated with psychological needs ($r = .32, p < .001$). Descriptive statistics and correlation of variables are presented in Table 2.2

Table 2.2. *Correlation of model variables and descriptive statistics.*

Variable	1	2	3	4	Mean (SD)
1. Fatigue	-	-.30*	-.46**	-.14	5.26 (1.29)
2. Self-Compassion		-	.44**	.23**	3.32 (.76)
3. Psychological Needs			-	.32**	3.94 (1.15)
4. Physical Activity	-.14*	.23**	.32**	-	261.78 (376.35)

Note: * $p < .05$, ** $p < .001$; coefficient α shown on diagonals.

In this sample, 67.32% ($n = 171$) of participants reported fatigue interfering with their activities. 31.89% ($n = 81$) participants reported that their fatigue somewhat interfered, and 35.43% ($n = 90$) participants reported that it usually or always interfered with their activities. When evaluating their engagement in self-compassion, 35.04% ($n = 89$) of participants reported engaging in self-compassion rarely or almost never, while only 21.65% ($n = 55$) reported engaging in self-compassion often or almost always. Among psychological needs, 40.55% ($n = 103$) of individuals reported feeling low competence for engaging in exercise, 36.61% ($n = 93$) reported feeling low relatedness to others in exercise, and 15.75% ($n = 40$) reported feeling a low sense of autonomy for directing their exercise.

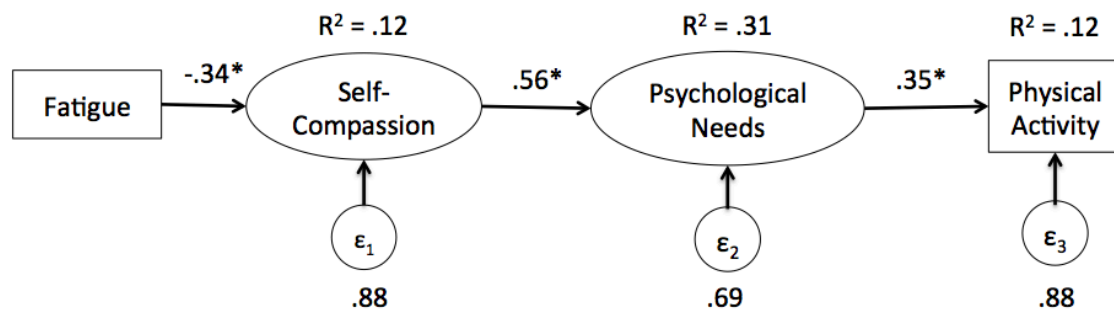
Self-reported physical activity ranged from 0 minutes per week to 2580 minutes per week, and included mild, moderate, and vigorous activity. The average time for engaging in physical activity per week was 264 minutes per a week, however, 23.62% ($n = 60$) of participants reported engaging in no physical

activity in the past seven days, and 28.34% ($n = 72$) of exercisers engaged in less than 150 minutes of mild, moderate, or vigorous physical activity per week.

Model Testing

Fit statistic results demonstrated a less than acceptable fit for Reyes' conceptual model ($\chi^2_{(19)} = 65.84$, $p = .000$; RMSEA = .10; CFI = .94; TFI = .92; SRMR = .07). Results for the tested model are depicted in Figure 2.1, and Table 2.3 summarizes fit-indices.

Figure 2.1. *Reyes' conceptual model of self-compassion.*



Note: $*p < .0001$. Path coefficients were denoted above/next to the lines. Multiple square correlation shows variances explained by self-compassion, psychological needs, and physical activity, and is denoted the above the variable.

In Reyes' model, the results showed that fatigue negatively predicts self-compassion ($\beta = -.34$, $p < .0001$, CI: $-.45, -.23$); self-compassion significantly predicts psychological needs ($\beta = .56$, $p < .0001$, CI: $.44, .68$); and psychological needs fully mediates the relationship between self-compassion and physical activity behavior, and positively predicts engagement in physical activity ($\beta = .35$, $p < .0001$, CI: $.24, .46$). In the path model, fatigue explained 11.74% of the variance in self-compassion, which, in turn, explained 31.35% of the variance in

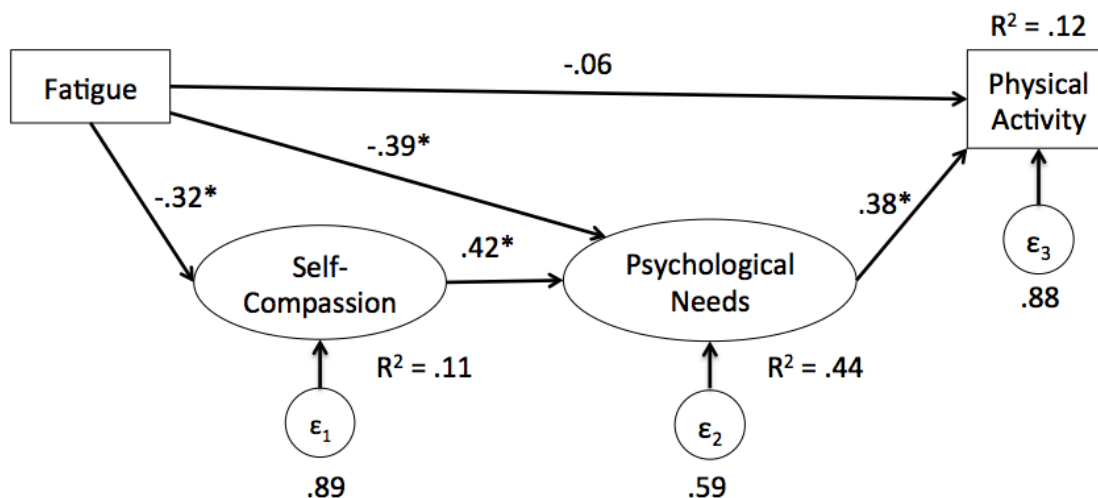
psychological needs, which then explained 12.14% of the variance in physical activity.

The alternative model added paths to examine the direct effects of fatigue on physical activity and psychological needs. The results indicated improved model fit ($\chi^2_{(17)} = 30.45$, $p = .02$; RMSEA = .06; CFI = .98; TLI = .97; SRMR = .04). Model fit statistics are presented in Table 2.3.

Table 2.3. *Comparison of fit indices between Reyes' conceptual model and the alternative model.*

	χ^2 (df), p	RMSEA	CFI	TLI	SRMR
Reyes' Model	65.84 (19), $p = .0001$.10	.94	.92	.07
Alternative Model	30.45 (17), $p = .02$.06	.98	.97	.04

In the alternative model, fatigue has not only an indirect relationship with psychological needs through SC ($\beta = -.14$, $p < .0001$, CI: -.20, -.07), but also a direct relationship with psychological needs ($\beta = -.39$, $p < .0001$, CI: -.51, -.28). Additionally, fatigue only has indirect relationships with physical activity ($\beta = -.15$, $p < .0001$) through psychological needs. The direct relationship between fatigue and physical activity was small and non-significant ($\beta = -.06$, $p > .05$, CI: -.09, .21), which was surprising. In the alternative path model, fatigue explained 10.54% of the variance in self-compassion, which, in turn, explained 43.51% of the variance in psychological needs, which then explained 12.44% of the variance in physical activity. Results for the alternative model are depicted in Figure 2.2.

Figure 2.2. *Alternative Model.*

Note: $*p < .0001$. Path coefficients were denoted above/next to the lines. Multiple square correlation shows variances explained by self-compassion, psychological needs, and physical activity and is denoted the below or above the variable.

Discussion

The main purposes of this study were: (1) to test a model of the transformation of suffering through self-compassion into psychological needs supporting self-determined motivation and physical activity behavior among individuals with MS; and (2) to test an alternative model examining the effects of fatigue on psychological needs, and physical activity behavior. The results from this study expand our understanding of behavioral theory for individuals with MS.

Fatigue can be a debilitating symptom that prevents individuals with MS from engaging in healthy behaviors. In this sample, the majority of participants (67.32%) reported fatigue interfering with their activities. Consequently, fatigue negatively predicted engagement in physical activity, self-determined motivation, and self-compassion, which was expected. Previous studies have demonstrated that fatigue may limit exercise and physical activity for individuals with MS (Smith, Olson, Hale, Baxter, & Schneiders, 2011; Stroud et al., 2009; White & Dressendorfer, 2004), although it has also been shown that engaging in physical

activity reduces fatigue in this population (Kargarfard, Etemadifar, Baker, Mehrabi, & Hayatbakhsh, 2012; Motl & Pilutti, 2012). In Reyes' model, fatigue negatively predicted physical activity through self-compassion and psychological needs. It was expected that in the alternative model, fatigue would have negative direct relationships with self-compassion, psychological needs and physical activity. Results showed fatigue significantly negatively predicted self-compassion and psychological needs directly. However, there was no direct effect of fatigue on physical activity, which was surprising. These findings suggest that fatigue influences engagement in physical activity through diminishing self-determined motivation for individuals with MS. Interventions seeking to increase physical activity should not overlook motivation as a critical mechanism that affects activity. Strategies that may be effective for improving psychological needs supporting self-determined motivation during periods of fatigue may include: (1) teaching individuals to adapt physical activity for mobility impairments and to avoid exacerbating fatigue; (2) planning for physical activity, setting realistic goals, anticipating barriers, and utilizing rewards; and (3) creating socially supportive environments through MS specific exercise programs.

Both models demonstrate that self-compassion significantly predicts psychological needs related to exercise, which is consistent with studies in the general population. It has been established that self-determination theory provides a promising framework for understanding the relationship between motivation and physical activity involvement (Magnus & Kowalski, 2010; Sirois, 2015), and it has been suggested that self-compassion fosters autonomous motivation in the exercise domain (Neff, 2003). Additionally, both self-compassion and self-determination support health promoting-behaviors (Magnus & Kowalski, 2010). Recent literature has revealed that social connection plays an important role in exercise engagement for this population (Christensen, Brincks, Schnieber, & Soerensen, 2016). Self-compassion may facilitate self-determined motivation by helping individuals feel less isolated and therefore increasing relatedness to others. Furthermore, self-compassion may encourage individuals

to take a mindful view of their condition which may allow them to feel more competent and autonomous in their activity choices and their ability to adapt exercise to meet their changing needs.

Because individuals with MS are typically sedentary, applying the alternative behavior change model of self-compassion has the potential to improve engagement in physical activity. In our sample, 52% of participants engaged in either no exercise or less than the minimum recommendations of 150 minutes of physical activity per week. Teaching individuals with MS to engage in self-compassion during difficult times may provide an alternative means of coping with debilitating symptoms such as fatigue, pain, and depression. Self-compassion may allow individuals to reframe their situation, and take a more mindful and kind approach to managing symptoms and participating in physical activity. This could potentially help individuals with MS engage in adapted or light forms of physical activity, even on days when they feel fatigued or have relapsing conditions.

Future directions for self-compassion research among individuals with MS may seek to understand what is affecting the relationship between psychological needs supporting self-determined motivation for exercise and actual engagement in physical activity. Qualitative research could provide more detailed information on how individuals with MS engage in self-compassion and how it impacts self-care behaviors, especially during difficult times. Future interventions should aim to teach self-compassion as strategy to improve motivation and help individuals engage in adapted exercise on days when they are experiencing fatigue. Studies may also seek to determine other causes of “suffering” in this population, such as disability status and chronic pain, and the differences between groups of high fatigue and low fatigue. Lastly, researchers could examine participants’ intentions for engaging in physical activity, as well as perceived barriers between motivation and behavior, to better understand why self-determined motivation is not translating into actual physical activity for individuals with MS.

While this study had encouraging results, readers should be cautious with generalizing these findings to other groups. This study was based on a convenience sample of individuals who participated in education and advocacy groups online and in person, as well as MS specific support groups and exercise groups. Because there is currently no national demographic data on individuals with MS, we were unable to determine if the sample in this study is representative of the entire population of individuals with MS in the United States. Because the majority of individuals were recruited online through social media ads and flyers, it was not possible to calculate the return rate for how many individuals viewed the online survey and how many participated. We expected participants to answer questionnaires and inclusion criteria truthfully and to the best of their knowledge. However, 33% ($n = 84$) of individuals did not report their age in the demographic survey. This failure to report age might have resulted in individuals participating in the survey who were older than the inclusion age. Further, physical activity behavior was assessed through a self-report measure, which requires individuals to recall their mild, moderate, and vigorous activity over the past seven days. Self-reported physical activity may result in biased reporting of actual behavior. Additionally, the data in this study are cross-sectional, which limits the ability to determine causality.

Conclusion

Individuals with MS face fatigue, disability, and unpredictable acute attacks or relapses of symptoms. Understanding how behavioral theory and self-compassion reframe individuals' experiences of their condition and increase motivation to engage in self-care behaviors can help health professionals develop effective interventions to improve overall wellness for individuals with MS or similar chronic conditions.

To date, self-compassion studies have primarily focused on reducing negative and risky health behaviors, rather than promoting positive health

behaviors such as physical activity. These results lay the groundwork for studies seeking to understand how to increase positive health behaviors through the cultivation of self-compassion for individuals with MS and other chronic conditions and acquired disabilities. The Reyes' model furthers our understanding of self-compassion on behavior change by examining the relationship between self-compassion and psychological needs related to self-determined motivation in the exercise domain. Furthermore, the alternative model provides insight into how symptoms like fatigue impact engagement in physical activity through motivation, providing a foundation to improve behavior in this population. These results can serve as a behavioral framework for future studies on psychosocial constructs and behavior change in this population.

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Chapter 3: Manuscript 2

Examining a mechanism by which self-compassion influences health-related
quality of life for individuals with Multiple Sclerosis

Abstract

The purpose of this study was to examine the roles of self-compassion and resilience on health-related quality of life for individuals with Multiple Sclerosis (MS) using mediation analysis. Two hundred fifty-nine adults with MS from MS advocacy, support, exercise, and education groups around the United States participated in the study. Participants' self-compassion, health-related quality of life (HRQoL), and resilience were measured by a survey. A simple mediation analysis was conducted to examine the relationships between the independent variable, self-compassion, the depended variable, HRQoL, and the mediating variable, resilience, using path analysis. Results showed a significant direct effect between self-compassion and health-related quality of life ($\beta = .49, p < .0001, CI: .37 - .61$), as well as an indirect relationship through resilience ($\beta = .18 p < .0001, CI: .17, .47$). The total effects of self-compassion on HRQoL are significant ($\beta = .67, p < .0001, CI: .33, .79$). These results contribute to the theoretical knowledge of how self-compassion influences HRQoL in this population. For individuals with MS, engaging in self-compassion may provide a strategy to cope with debilitating conditions and reframe perceptions of their health.

Introduction

Multiple Sclerosis (MS) is an autoimmune condition that affects the central nervous system and impacts the lives of over 400,000 individuals in the US (National MS Society, 2013). MS is characterized by periods of exacerbations of symptoms, which may involve balance and mobility impairments; affect vision, speech, hearing or cognition; and cause extreme fatigue, spasticity, and paresis (National MS Society, 2013). As individuals experience relapses of disease and face greater disability, they have increased difficulty engaging in activities of living, which decreases functional independence and reduces their quality of life (Benito-Leo'n, Morales, Rivera-Navarro, & Mitchell, 2003; Miltenburger & Kobelt, 2002; Mitchell, Benito-Leo'n, Gonzales, & Rivera-Navarro, 2005).

Health-related quality of life (HRQoL), which is one's perception of their overall wellbeing as it relates to health, has been an indicator of wellness and widely studied among populations with chronic disease, trauma, and disability (Krahn, Horner-Johnson, Hall, Roid, Andresen, & Fujiura et al., 2014; Vitali, 2011). Individuals with MS have reported significantly lower HRQoL than the general population, perhaps because of their associated conditions and accumulation of disabling symptoms (White & Dressendorfer, 2004). Health professionals are challenged to find ways to improve health and wellness in this population (Plow, Finlayson, & Cho, 2011). Improving engagement in self-compassion is one behavior that has the potential to improve HRQoL for individuals with MS.

Self-compassion is defined as the desire to ease one's own suffering through offering self-kindness, and nonjudgmental understanding (Neff, 2003). Through these actions, individuals can comfort themselves in times of distress, acknowledge their pain or struggle, and know that they are not isolated in their experiences. Cultivating self-compassion can be beneficial when dealing with difficult life events, such as chronic disease, and when feelings of inadequacy arise, such as engaging in physical activity with a disability (Neff, 2003; Wren,

Somers, Wright, Goetz, Leary, Fras et al., 2012). Being self-compassionate may increase one's ability to take a mindful attitude toward their condition, therefore being more accepting of their experience while still engaging in meaningful daily activities (Wren et al., 2012). Since individuals with MS face extraordinary fatigue and acute attacks, they may endure greater psychological challenges and negative affect (due to "suffering") than the general population. Therefore, self-compassion may play an important role in psychological health, resilience, and the perception of one's HRQoL.

Resilience is one attribute that has been linked with improved quality of life for this population and has been conceptualized as the capacity to persist or bounce back through positive adaptation in times of stress or adversity (Bonanno, 2004; Luthar, Cicchetti, & Becker, 2000; Silverman, Verrall, Alschuler, Smith, & Ehde, 2016). However, individuals with MS have reported lower levels of resilience compared to the general population, and other acquired disability groups (Terrill, Molton, & Alschuler, 2016). A recent qualitative study explored barriers and facilitators to resilience, and the meaning of resilience, among individuals with MS (Silverman et al., 2016). Participants described several facilitators that supported resilience, which included psychological adaptation and social connection. Psychological adaptation included awareness of challenges (mindfulness), acceptance, and self-compassion, while social connectedness included support from peers with MS as well as family and friends. The results from Silverman's study (2016) support the importance of mindfulness, social connectedness, and self-compassion as promoters of resilience in this population.

While there has been qualitative support for resilience and self-compassion promoting quality of life in this population, there is a need to understand the mechanisms by which these effects occur. Therefore, we seek to advance the understanding of the mechanisms by which self-compassion contributes to overall wellness for individuals with MS. The purpose of this study

was to examine the roles of self-compassion and resilience on health-related quality of life. It is hypothesized that resilience will partially mediate the relationship between self-compassion and HRQoL for individuals with MS.

Methods

Participants

Two hundred and fifty-nine individuals with MS participated in the study. Inclusion criteria were 1) between the ages of 18-65, and (2) having a medical diagnosis of MS. Participants may have had a medical diagnosis of any of the four types of MS (i.e., relapse-remitting, primary-progressive, secondary-progressive, and progressive-relapsing).

Participants were predominantly white (90.31%) females (84.17%) with a mean age of 48.55 (SD = 10.47). The average BMI was 28.32 (SD = 7.93; range: 17.13 – 70.31), and 59.64% (n = 143) of individuals reported being in the overweight or obese categories. Seventy-three percent of participants reported having a relapse-remitting MS course, and 18.22% were in secondary-progressive. Time since last acute attack was reported at greater than twelve months for 53.85% of individuals, followed by less than 3 months for 23.67% of individuals. Thirty-eight percent of participants were employed for wages, and 35.27% reported being unable to work due to their MS. Forty-eight percent of participants had a diagnosis of MS for 10 years or less (n = 123), 31.50% had MS for 11 to 20 years (n = 80), and 20.08% had MS for between 21 and 49 years (n = 51). The majority of participants reported their health status as good, very good, or excellent (65.05%). Table 3.1 presents demographic information for this study.

Table 3.1. *Demographics of participants*

Demographics		Percent	Frequency (n)
<i>Sex (n = 259)</i>			
	Male	15.77%	41
	Female	84.23%	218
<i>Race (n = 258)</i>			
	White	90.31%	233
	Black	1.55%	4
	Native American	1.55%	4
	Latino	3.88%	10
	Not Listed	0.78%	2
	Did not wish to disclose	1.94%	5
<i>MS Type (n = 258)</i>			
	Relapse-remitting	73.26%	189
	Secondary-progressive	18.22%	47
	Primary-progressive	7.36%	19
	Progressive-Relapsing	1.16%	3
<i>Time since last acute attack (n = 247)</i>			
	Less than 3 months	22.67%	56
	3 to 6 months	10.12%	25
	7 to 9 months	4.86%	12
	10 to 12 months	8.50%	21
	Greater than 12 months	53.85%	133
<i>Health Status (n = 258)</i>			
	Poor	5.81%	15
	Fair	28.68%	74
	Good	36.43%	94
	Very good	24.03%	62
	Excellent	5.04%	13
<i>Employment (n = 258)</i>			
	Employed for wages	38.37%	99
	Self employed	3.88%	10
	Out of work greater than 12 months	6.20%	16
	Out of work less than 12 month	1.55%	4
	Homemaker	5.81%	15
	Student	1.16%	3
	Retired	7.75%	20
	Unable to work	35.27%	91
<i>BMI (n = 248)</i>			
	< 18.5	2.02%	5
	18.5 – 24.9	40.32%	100
	25.0 – 29.9	26.02	67
	≥ 30.0	30.65%	76

Note: Differences in n resulted when participants did not respond to certain demographic questions.

Measures

Participants completed a survey that included three questionnaires and demographic information for a total of 60 questions: Revised Connor-Davidson Resilience Scale (CD-RISC10), Self-Compassion Scale (SCS), and Function Neutral Health-Related Quality of Life Short Form (FuNHRQOL-SF). The demographic questionnaire included items on current health status, and information about their MS (MS type, date of diagnosis, time since last relapse).

The SCS (Neff, 2003) measured individuals' self-compassion on 5-point Likert-type scale ranging from 1 (almost never) to 5 (almost always). This 26-item scale has three paired subscales: (1) self-kindness vs. judgment, (2) mindfulness vs. over attachment, and (3) common humanity vs. isolation. Previous research demonstrated test-retest reliability ($r = .80-.93$) (Neff, 2003), and in our sample, internal consistency coefficient was $\alpha = .93$. The measure includes questions such as, "When I'm going through a very hard time, I give myself the caring and tenderness I need," and, "I'm disapproving and judgmental about my own flaws and inadequacies." Items from judgment, over-attachment, and isolation were reverse coded, and each of the three subscale means were summed to get a total mean for self-compassion.

A revised CD-RISC10 was used to measure individuals' resilience, or ability to cope with stress (Campbell-Sills & Stein, 2007; Connor & Davidson, 2003). The CD-RISC10 is a self-report measure comprised of ten items intended to measure resilience. Responses are given on a 5-point Likert scale, and includes questions such as, "I tend to bounce back after illness or hardship," and, "I am able to adapt to change." Total mean score was used to identify individual's perception of their resilience, with a higher score associated with higher

resilience. The measure demonstrated good internal consistency in a previous study ($\alpha = .85$) (Campbell-Sills & Stein, 2007), and in this study sample ($\alpha = .86$).

The FNHRQOL-SF (Krahn et al., 2014) was used to measure individuals' HRQoL. This 13-item measure has five dimensions: physical, mental, and social health, life satisfaction, and environment. Participants answer questions in these five domains with a 7-point Likert-type scale ranging from 1 (never or almost never) to 7 (always or almost always). In other measures of HRQoL health is not divorced from function. These measurement tools create a bias against individuals with disability who may have less functional ability, but not necessarily poorer health. Thus, the FNHRQOL measure is unique because it removes bias against individuals with disabilities in the HRQoL domain, thereby measuring HRQoL distinct from function and with regard to the process of adapting to disability (Krahn et al., 2014). This measure includes questions such as, "Were you satisfied with your daily life in general?", "Did your life have purpose?", and "Did you get where you needed to go?" The short-form demonstrated good internal consistency in this study ($\alpha = .91$). Three items were reverse coded, and total mean score was used to obtain perceived HRQoL, with a higher score associated with a higher perceived HRQoL.

Procedures

This study employed a convenience sample of individuals with MS. Participants were recruited from the National MS Society's local chapters and support groups, and from other MS advocacy groups and exercise programs through: email, printed flyers, social media advertisements, and in-person survey distribution.

Recruitment occurred over four months. For the email recruitment, an initial contact email was sent out to twenty-one individuals with (1) a description on the study, (2) a link to complete the online questionnaire, and (3) a deadline to complete the questionnaire. After ten days, a second reminder email was sent out with the link to the questionnaire. A final follow-up email and thank you was

sent out ten days after the second contact.

Additionally, the researcher attended MS events in the area (i.e., informational events and conferences) to distribute flyers and printed surveys with postage paid return envelopes, and collect email addresses of individuals interested in participating. Approximately 90 printed survey packets were distributed to individuals attending MS events and clinics and twelve were returned. Printed flyers with a description of the study, a link to complete the survey, and contact information of the research team were also distributed to social support groups and exercise programs.

Online advertisements were posted through social media outlets (Facebook), posted to MS advocacy webpages, and sent out through e-blasts and e-newsletters. The National MS Society, the Multiple Sclerosis Foundation, and the Multiple Sclerosis Association of America all assisted with advertising the research study through their webpages and list servers. For the online social media recruitment, advertisements were posted with a brief description of the study and target population, a link to complete the survey, and contact information for the research team. Advertisements were reposted every ten days for three recruitment attempts. The university institutional review board approved all study activities, and informed consent was obtained from all participants.

Data Analyses

Demographic data (age, sex, race/ethnicity, BMI, overall health status, time since last acute attack, and duration and type of MS) were analyzed for descriptive statistics, including means and standard deviations.

A total of 339 participants were recruited. Sixteen participants were not within the 18 - 65 age range and one participant did not have a medical diagnosis of MS. Bennett (2001) and Rubright, Nandakumar, and Glutting (2014) recommend excluding participants with greater than ten percent missing data from the analyses, as large amounts of missing data can impact the validity of

results. Therefore, after participants not meeting inclusion criteria were removed, participants who had more than 10% missing data ($n = 63$) were removed. This resulted in 259 participants who were retained for the final model testing analysis. The final participants were comprised of 3.1% (8) from printed survey packets, 7.7% (20) from email recruitment, 54.4% (141) from social media advertisement, and 34.7% (90) from flyer distribution

Normality was checked through tests of skewness and kurtosis, and results showed that data was not normally distributed (skewness: $-.42$, $p < .006$; kurtosis = 3.36 , $p < .2$). Therefore, to obtain a more accurate relationship between endogenous and exogenous variables, the bootstrap resampling method was used with 1,000 random resamples and 95% bias-corrected confidence intervals (Efron, 1988; Zhu, 1997). Correlation analyses were first conducted to identify the interrelationships among the model variables.

To answer the research question, path analysis was used to examine the measurement model of self-compassion, and the direct and indirect effects of self-compassion on HRQoL. In this study, the independent variable was self-compassion, the dependent variable was HRQoL, and the mediating variable was resilience. In the mediation analysis, the direct effect is noted as c' and the indirect effects are the product of “a” and “b”. In the indirect effect, “a” is the path from the independent variable to the mediating variable, and “b” is the path from the mediating variable to the dependent variable. Total effect (c) is the sum of the direct and indirect effects ($ab + c' = c$).

Model fit was assessed using the Chi-square (χ^2) test, comparative fit index (CFI), Tucker-Lewis fit index (TFI), root mean square error of approximation (RMSEA), and the standardized root mean square residual (SRMR). While acknowledging fit indices are depended on sample size, Hu and Bentler (1999) recommend a cutoff value close to .95 for fit indices (CFI & TFI). They also recommended a cutoff of .09 for SRMR when used in combination with $RMSEA > .06$ (Hu & Bentler, 1999). For RMSEA, values less than .05 indicate a

close fit, values in the range of .05 to .08 indicate a fair fit, values in the range of .08 to .10 indicate a mediocre fit, and values greater than .10 indicate a poor fit (Browne & Cudek, 1992; McCallum & Austin, 2000). Finally, Hu and Bentler (1999) concluded that analyses with small sample sizes ($N \leq 250$), the recommended combinational rules have a slight tendency to overreject true models when data does not meet normality assumptions. Statistical analyses were conducted with Stata v.13 (StataCorp, 2013) and significance level was set at $p < 0.05$.

Results

The results of correlation analyses indicate that self-compassion was significantly and positively associated with HRQoL ($r = .65, p < .0001$), and resilience ($r = .59, p < .0001$). Resilience was significantly and positively associated with HRQoL ($r = .60, p < .0001$). Descriptive statistics and correlation of model variables are presented in Table 3.2.

Table 3.2. *Correlation of model variables and descriptive statistics.*

Variable	1	2	3	Mean	SD
1.Resilience	-	.59*	.60*	3.60	.64
2.Self-Compassion	-	-	.65*	3.32	.76
3.Health-Related Quality of Life	.60*	.65*	-	4.89	1.24

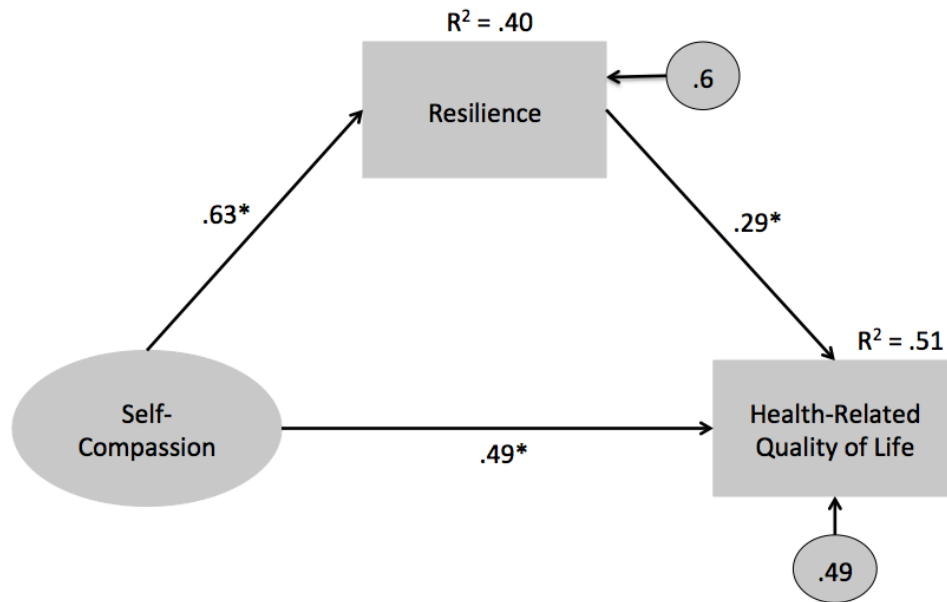
Note: * $p < .0001$; coefficient α shown on diagonals.

Fit statistic results demonstrated good fit for the tested model ($\chi^2_{(4)} = 15.50, p = .004$; CFI = .99; TLI = .97; RMSEA = 0.10; SRMR = 0.02). In the mediation model, self-compassion and resilience explained approximately 51% of the variance in HRQoL. Self-compassion explained 40% of the variance in resilience.

The results of the mediation analysis indicated that self-compassion not only has direct effects HRQOL ($\beta = .49, p < .0001, CI = .37 - .61$), but also has

indirect effects on HRQOL through resilience ($\beta = .18, p < .0001, CI: .17, .47$). The total effects of self-compassion on HRQoL are significant ($c = .67, p < .0001$). Results for the tested model are depicted in Figure 3.1 and Table 3.3

Figure 3.1. *Mediation model of self-compassion and HRQoL*



NOTE: * $p < .0001$. Path coefficients were denoted above/next to the lines. Multiple square correlation shows variances explained by resilience and HRQoL and is denoted the above the variable.

Table 3.3. *Path coefficients, variance, standard error, and confidence intervals*

Path	β	R^2	SE	BC CIs
Self-Compassion \rightarrow HRQoL (c')	.49*	-	.06	.37 - .61
Self-Compassion \rightarrow Resilience (a)	.63*	.40	.04	.55 - .71
Resilience \rightarrow HRQoL (b)	.29*	-	.06	.17 - .41
Self-Compassion \rightarrow HRQoL, mediated by Resilience (ab)		.51	.06	.17 - .47

NOTE: * $p < .0001$. Variance explained (R^2), standardized regression coefficients (β), standard error (SE), and bias-corrected confidence intervals (CIs).

Discussion

The purpose of this study was to contribute to the conceptual understanding of the mechanisms by which self-compassion impacts HRQoL using mediation analysis for individuals with MS. Current literature has suggested that self-compassion and resilience are important factors that positively influence HRQoL in MS populations and individuals with chronic conditions (Silverman et al., 2016.; Vitali, 2011). This study examines not only the direct impacts of self-compassion on HRQoL, but also how self-compassion predicts HRQoL. This study revealed that self-compassion also indirectly influences HRQoL through resilience.

In this study, self-compassion had a significant direct effect on HRQoL, which was expected. Studies have shown support for self-compassion's direct influence on overall wellness in the general population (Ferguson, Kowlaski, Mack, & Sabiston, 2014). Recent literature has demonstrated that improving feelings of acceptance may diminish the mental and emotional impact of living with a chronic disease. One study examined the role of self-compassion as a moderator between physical health and subjective well-being in the elderly (Allen et al., 2012). The results showed that in individuals with relatively good physical health, their perception of their subjective wellness was high regardless of their level of self-compassion. However, in participants with poorer physical health and disability, self-compassion was positively related to greater subjective wellness. Additionally, the individuals who were more self-compassionate were more willing to use assistive devices such as mobility aides and hearing aides. The results from this study suggest that when living with disability or chronic condition, self-compassion may play a critical role in bolstering one's perception of wellness or HRQoL, and willingness to seek support (Allen et al., 2012).

Furthermore, the findings of this study are consistent with other recent literature linking self-compassion with resilience among individuals with chronic disease (Allen et al., 2012; Silverman et al., 2016; Vitali, 2011). Self-compassion

has been related to improving individuals' resilience and coping related to life stressors such as chronic pain and disability, while increasing perceived well-being and quality of life (Allen et al., 2012; Magnus, Kowalski, & McHugh, 2010). Self-compassion in the general population has been linked with increasing positive affect, and decreasing depression and anxiety (Neff, 2009; Neff, Kirkpatrick, & Rude, 2007). Previous research among the general population and populations aging into chronic conditions support self-compassion as a facilitator of resilience, and a behavioral construct by which HRQoL may be improved for individuals with MS. This may happen as individuals who engage in self-compassion take a more balanced or mindful view of their condition and feel less isolated when debilitating symptoms arise, allowing the individual to reframe negative perceptions and improve their ability to rebound from exacerbations of symptoms or disabling events.

Based on the results of this study, it is reasonable to expect that engaging in self-compassion may provide a strategy to cope with debilitating conditions and reframe perceptions of personal health for individuals with MS. Additionally, increasing resilience may help individuals overcome stressful and traumatic events and experience quality of life with disability (Vitali, 2011). Resilience and self-compassion are both modifiable constructs that can be targeted by programs seeking to improve overall wellness. Future interventions could use strategies to foster social connection, such as peer support groups, and mindfulness practices to increase resilience through engagement in self-compassion. Support groups may help facilitate connection to others experiencing similar symptoms and help individuals feel less isolated when relapsing symptoms occur. A recent focus group study that evaluated participants' experiences with an intervention aiming to increase physical activity engagement and social support among a group of individuals with MS found that participants felt more connected and benefitted from the support of other participants, rather than from those who did not have MS (Nery-Hurwit, 2014). One participant summarized this sentiment by stating, "...when you have chronic condition that the rest of the world cannot relate to. If

you're around others who know and get it and understand what you're talking about, it's just very gratifying." Additionally, teaching individuals with MS mindfulness practices may enable them to keep a sense of perspective, combat negative thoughts and feelings, and promote flexibility and positive coping strategies when they are experiencing chronic fatigue or mobility impairments. These strategies may include mindfulness meditation, journaling, and stress management. Lastly, increasing resilience may be approached through teaching specific coping mechanisms and positive adaptations related to the uniquely unpredictable nature of MS conditions. These may include positive cognitive restructuring, support seeking, and problem solving, as suggested by Skinner and colleagues (Skinner, Edge, Altman, & Sherwood, 2003). Targeting these strategies may help foster resilience when unpredictable exacerbations or acute attacks occur, allowing individuals with MS to maintain a better HRQoL.

While this study had encouraging results, readers should be cautious with extrapolating these findings to other groups of individuals with disability. Although these relationships should be tested among populations with chronic conditions and mobility impairments, such as Parkinson's, Amyotrophic Lateral Sclerosis (ALS), Muscular Dystrophy, Fibromyalgia, Rheumatoid Arthritis, and Spinal Cord Injury. This study was based on a convenience sample of individuals who participated in education and advocacy groups online and in-person, as well as MS specific support groups and exercise groups. Because there is currently no national demographic data on individuals with MS, we were unable to determine if the sample in this study is representative of the entire population of individuals with MS in the United States. Because the majority of individuals were recruited online through social media ads and flyers, it was not possible to calculate the return rate for how many individuals viewed the online survey and how many participated. We expected participants to answer questionnaires and inclusion criteria truthfully and to the best of their knowledge. However, 34% (n = 88) of individuals did not report their age in the demographic survey. This failure to report age might have resulted in individuals participating in the survey who were

older than the inclusion age. . Additionally, the data in this study are cross-sectional, which limits the ability to determine causality.

Conclusion

These findings have encouraging implications for use in populations with MS and other disabilities. Because individuals with MS face acute attacks, and often sudden worsening of symptoms and accumulation of disability, they endure greater psychological challenges and negative affect than the general population. Self-compassion and resilience are constructs that may help to re-shape how individuals with chronic conditions perceive their state of being and ability, as well as their HRQoL.

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Chapter 4: General Conclusion

Conclusion

Individuals with Multiple Sclerosis (MS) report experiencing poorer health, lower quality of life, and engaging in less physical activity than the general population. Health professionals are challenged to find ways to improve their engagement in health behaviors and increase quality of life (Plow, Finlayson, & Cho, 2011). The results in this dissertation support self-compassion as a behavioral construct that may improve healthy behaviors and quality of life for this population.

The first study examined a model grounded in Reyes' conceptual model of self-compassion in a sample of individuals with MS, and examined an alternative model of fatigue and physical activity. The results demonstrated that Reyes' conceptual model is not appropriate for use in MS populations, however the alternative model adequately fits the data and explained more variance than Reyes' model. Additionally, the alternative model showed a significant negative direct relationship of fatigue on self-determined motivation to exercise, but not on self-reported physical activity engagement. This alternative model of self-compassion's can serve as a behavioral framework for future studies on psychosocial constructs and behavior change.

The second study examined the underlying mechanism by which self-compassion influences health-related quality of life (HRQoL) in a sample of individuals with MS. Resilience partially mediated the relationship between self-compassion and HRQoL. As individuals who engage in self-compassion take a more balanced or mindful view of their condition and feel less isolated when debilitating symptoms arise, this may allow them to reframe negative perceptions and improve their ability to rebound from exacerbations of conditions or disabling events.

In conclusion, self-compassion has the potential to impact self-determined motivation for engaging in physical activity, support resilience, and improve HRQoL for individuals with MS. The two studies in this dissertation contribute to

deepening our theoretical knowledge on self-compassion and behavior change, and the mechanisms by which self-compassion impacts wellness for individuals with MS. These findings have encouraging implications for use in populations with MS and chronic disabling conditions.

Future directions for self-compassion research among individuals with MS may include qualitative studies, and development of wellness interventions. Qualitative research could provide rich information on how individuals with MS engage in self-compassion; how it impacts resilience and self-care behaviors, especially during difficult times; and how self-compassion contributes to their overall wellness. Future interventions should aim to teach self-compassion as strategy to improve motivation, resilience, and quality of life, and help individuals engage in adapted exercise on days when they are experiencing fatigue.

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APPENDICES

Appendix A: Review of Literature

The purpose of this literature review is to provide the readers with information on Multiple Sclerosis, current states of physical activity and quality of life among individuals with MS, an overview of Reyes' Self-Compassion Model, recent research on self-compassion and health behavior, and studies on self-compassion applied to individuals with chronic conditions and disability. This information provides rationale for the current study.

What is Multiple Sclerosis?

Multiple Sclerosis (MS) is an autoimmune disease that affects the central nervous system, and is considered to be one of the most frequently experienced disabling conditions among young adults (Trapp & Nave, 2008), impacting the lives of over 400,000 individuals in the US (National MS Society, 2013). Epidemiological studies suggest a relationship between several environmental and genetic factors, which may lead to MS (National MS Society, 2013). There are studies that have shown that there is a reduced risk of developing MS for individuals living closer to the equator during their developmental years, and a greater risk for individuals living above 40 degrees latitude (Sturm & Gurevitz, 2014), which suggest there is a relationship with low vitamin D levels or sun exposure (Sturm & Gurevitz, 2014). Additionally, smoking and testing positive for previous Epstein-Barr viruses have been related to increased risk of developing MS (Sturm & Gurevitz, 2014).

MS occurs due to acute demyelination of nerve axons causing plaques or scar tissue to accumulate in the central nervous system (National MS Society, 2013; Sturm & Gurevitz, 2014). When the myelin sheath is damaged, the conductivity is diminished, causing nerve signals to be slowed down or completely impaired (Sturm & Gurevitz, 2014).

Symptoms and Diagnosis

Symptoms of MS typically appear between the ages of 20 and 40 years,

and affect women more often than men (Sturm & Gurevitz, 2014). Diagnosis is received when the MacDonald criteria are met, which includes documentation of lesions disseminated in space and disseminated over time (Polman, Reingold, Banwell, Clanet, Cohen, & Filippi, 2011). This means that individuals have one or more lesions in two or more areas of the central nervous system, and have new lesions appearing over time (Polman et al., 2011). Evidence of MS is found through MRI and cerebrospinal fluid analysis (Montalban, Tintore, & Swanton, 2010; National MS Society, 2013). Individuals with MS have a wide array of symptoms due to the broad central nervous system damage that occurs, and may present with motor symptoms such as spasticity, muscle weakness, numbness and tingling, and paralysis; cerebellar dysfunction, which may result in difficulty with coordination, balance, and gait abnormalities; neuropsychiatric disorders such as difficulty concentrating, memory loss, anxiety, and depression; fatigue; and heat intolerance (Markowitz, 2013; National MS Society, 2013; Sturm & Gurevitz, 2014). Currently, there is no cure for MS. Management of the disease primarily consists of suppressing the immune system through beta-interferons and glatiramer acetate to reduce the number of relapses or exacerbations, and reducing accumulated disability (National MS Society, 2013; Polman, Thompson, & Murray, 2002; Sturm & Gurevitz, 2014).

Types of MS

There are four courses of MS: relapse-remitting, secondary progressive, primary progressive, and progressive relapsing. Relapse-remitting is the most commonly experienced type of MS (MS Society, 2013) with 85% of individuals diagnosed with this course (Montalban, Tintore, & Swanton, 2010). It is characterized by periods of relapsing symptoms or attacks of inflammation, followed by periods of a relapse in symptoms (remissions) in which there is no apparent progression of the disease (Lublin & Reingold, 1996; National MS Society, 2013). Secondary progressive typically follows the relapse-remitting stage and is characterized by a progression of the condition either continuously

or punctuated by relapses or plateaus (Lublin & Reingold, 1996; National MS Society, 2013). Primary progressive is characterized by a continual worsening of the condition with no remissions (Lublin & Reingold, 1996; National MS Society, 2013). Progressive relapsing is the least common diagnosis with approximately 5% of individuals receiving this diagnosis at the onset, and is characterized by a continuous worsening of the condition, punctuated by occasional relapse or exacerbation of symptoms and some recovery, although MS has no true remissions (Lublin & Reingold, 1996; National MS Society, 2013). Individuals may maintain one condition course over their lifetimes, or progress to more severe condition courses. They often experience one of three patterns: episodes or attacks followed by complete or partial recovery; gradual decline in health and function; or a combination of the two (Sturm & Gurevitz, 2014).

Another characteristic of MS is the occurrence of acute attacks or exacerbations, which are the sudden onset of symptoms that impair the individual and contribute to disability (National MS Society, 2013; Polman et al., 2002). At least 85% of individuals with MS experience acute attacks or exacerbations (Polman et al., 2002). These acute attacks can vary in duration and severity, and often result in the accumulation of mobility impairments and progressive worsening of disability (National MS Society, 2013). During these acute attacks, individuals are often unable to complete activities of daily living, may be unable to care for themselves, and often experience exceptional fatigue and mobility disabilities such as paralysis. It is believed that these exacerbations are a result of focal areas of inflammation in the central nervous system (Polman et al., 2002). This inflammation causes damage to the myelin sheaths surrounding nerve fibers, disrupting the transmission of impulses (National MS Society, 2013). Little is known about the causes of the inflammation or what governs the level of recovery, however, one consistent precipitating factor is the occurrence of stressful life events (Polman et al., 2002).

MS and Quality of Life

Individuals with MS experience poorer health, and higher rates of comorbidities than the general population, as well as a decreased quality of life (Markowitz, 2013; White & Dressendorfer, 2004). For individuals living with MS, there are a wide variety of associated conditions (e.g., fatigue, chronic pain, lack of balance) and secondary conditions (e.g., depression, obesity, cardiovascular disease) that people may experience (White & Dressendorfer, 2004). As individuals develop secondary conditions and face greater disability, they have increased difficulty completing activities of daily living, which decreases functional independence and reduces their quality of life (Benito-Leo'n, Morales, Rivera-Navarro, & Mitchell, 2003; Miltenburger & Kobelt, 2002; Mitchell, Benito-Leon, Gonzales, & Rivera-Navarro, 2005; Petajan & White, 1999). For example, in a study examining quality of life across a wide range of chronic diseases (N = 15,000), individuals with MS reported some of the poorest quality of life, second only to individuals with Parkinson's (Sprangers, de Regt, Andries, van Agt, Bijl, & de Boer, 2000). Individuals with MS in this study also reported lower levels of physical and mental functioning compared to most other groups. The presence of comorbid conditions in this study also correlated with the poorest reported quality of life. For many individuals with MS, this leads to a cycle of degrading health and other disabling conditions (Mitchell et al., 2005; Petajan & White, 1999).

Physical Activity and MS

However, physical activity has been shown to improve health and quality of life in this population (Motl & Gosney, 2008; Tarakci, Yeldan, Huseyinsinoglu, Zenginler, & Eraksoy, 2013). For individuals with MS, regular activity can improve memory and mood, cardio respiratory fitness, muscle strength and endurance, and reduce fatigue (Dalgas et al., 2008; Motl & Pilutti, 2012), as well as help manage common MS symptoms, promote wellness, and increase participation in social activities (Mostert & Kesselring, 2002; Petajan & White, 1999). Mostert and

Kesselring (2002) conducted a randomized control trial examining the effects of a four-week exercise training program for individuals with MS (N = 37) on aspects of cardiovascular fitness, health status, fatigue, and physical activity. At the end of the intervention, individuals in the experimental group significantly increased their aerobic threshold (VO_2 + 13%; work rate + 11%) and their activity level (+17%), improved their health perception (vitality + 46%; social interaction + 36%), and had reported less fatigue. Additionally, the incidence of symptom exacerbation by physical activity was lower than expected (6%) (Mostert and Kesselring, 2002).

Changes in physical activity have been associated with change in function, and this change in function is associated with improvement in MS disability (Motl & McAuley, 2009). Furthermore, functioning has been reported as a mediator between physical activity and disability in this population (Motl & McAuley, 2009). In a cross-sectional study examining the associations between aerobic health, lower limb muscle strength, and cognitive function in individuals with MS (N = 62), results showed an association between aerobic capacity and strength with higher cognitive function in individuals with mild MS (Sandroff, Pilutti, Benedict, & Motl, 2015). Yet despite the reported benefits of maintaining an active lifestyle, people with MS are typically less active than the general population (McCullagh et al., 2008; Motl et al., 2005; Plow et al., 2011). Due to their chronic and often deteriorating condition, and a lack of engagement in health promoting activities such as physical activity, health practitioners are challenged to find ways to improve the health and quality of life for individuals with MS (Plow et al., 2011).

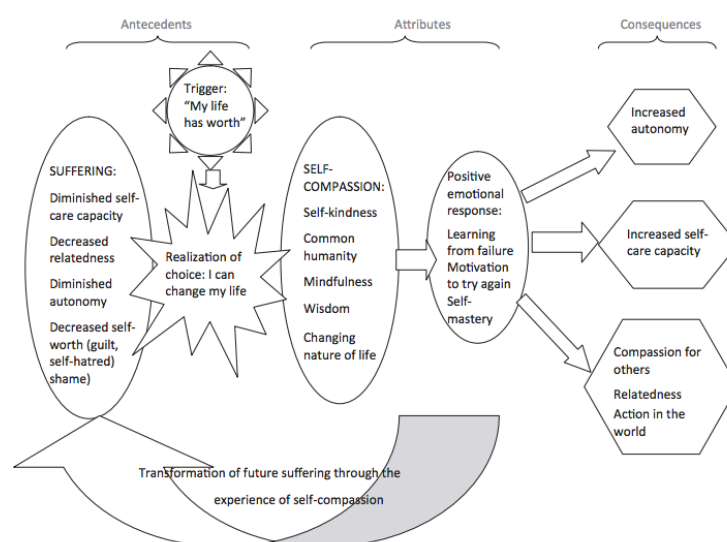
The Self-Compassion Model

Self-compassion is defined as the desire to relieve suffering and increase acceptance of oneself (Neff, 2003). Neff's model of self compassion is comprised of three components: 1) showing kindness to oneself instead of harsh judgment

and criticism; 2) viewing personal experiences as shared by others (common humanity) rather than isolating oneself; and 3) perceiving feelings as balanced (mindfulness) instead of over-identifying with them (Neff, 2003).

Reyes (2012) conceptualized a model of self-compassion, which includes antecedents, trigger, attributes, emotional response, and consequences. Reyes' proposed antecedent to self-compassion is suffering, which has three dimensions: intrapersonal, interpersonal, and contextual. Suffering leads to a diminished capacity to care for oneself, decreased ability to related to others, diminished autonomy, and decreased self-worth which is characterized by guilt and shame (Reyes, 2012). The proposed trigger to engaging in self-compassion is the realization that an individual's life has worth and they realize a choice to change their life. When one engages in self-compassion they increase their positive emotional response and motivation, which in-turn increases autonomy, capacity for self-care, and compassion and relatedness to others. This positive emotional response transforms future suffering through experiencing self-compassion (Reyes, 2012). Figure A.1 details this conceptual model of self-compassion (Reyes, 2012).

Figure A.1. Reyes' Conceptual Model of Self-Compassion.



Benefits of Self-Compassion

In the general population, self-compassion has been linked with increasing positive affect, and negative affect (Neff, 2009; Neff, Rude, & Kirkpatrick, 2007). Neff and colleagues (2007) examined the relationship between self-compassion and positive psychological health among 91 college students. Students were given self-report measures assessing self-compassion, self-esteem, negative affect, and anxiety, and then asked to respond to questions under a high stress situation (i.e., job interview). After the high stress situation was administered, students completed the anxiety measure again at post-test. The results showed that self-compassion had a significant positive association with positive affect, personal initiative, happiness, and optimism, and a significant negative association with negative affect, while buffering against negative emotion and anxiety.

Interventions targeting self-compassion have been successful at improving individuals' social connectedness, happiness, life-satisfaction, depression, anxiety, and stress in the long-term (Neff & Germer, 2013; Smeets, Neff, Alberts, & Peters, 2014). For example, in a randomized control trial of an 8-week mindfulness self-compassion program, participants in the experimental group significantly increased their self-compassion, mindfulness, life satisfaction, happiness, while significantly decreasing their depression, anxiety, and stress (Neff & Germer, 2013). These improvements to health outcomes were sustained over a six-month period (Neff & Germer, 2013). Studies have also demonstrated a correlation between self-compassion and perceived well-being (Hollis-Walker & Colosimo, 2011; Neff, Kirkpatrick, & Rude, 2007). In a study conducted by Neff and colleagues (2007), subjects participated in a Gestalt two-chair exercise, in which they challenged maladaptive, self-critical beliefs (Neff et al., 2007). Self-compassion scores, along with other measure of mental health and well-being, were collected one week before the intervention, and three weeks after the intervention. Results showed that increases in self-compassion were correlated

with increases in social connectedness, and decreases in self-criticism, depression, rumination and anxiety (Neff, Kirkpatrick, et al., 2007).

Self-Compassion and Health Behavior

Reyes' proposed model of self-compassion (2012) suggests that engaging in self-compassion provokes a positive emotional response, which increases motivation for self-mastery. In turn, this motivation leads to an increased self-care capacity, autonomy, and relatedness, which translates to action in the world or behavioral change (Reyes, 2012).

In a study conducted by Sirois and colleagues (2014) examining the effects of self-compassion on positive health behaviors and the role affect plays in explaining these mechanisms, results showed that self-compassion is significantly associated with the practice of positive health behaviors (i.e., physical activity, stress management, proper nutrition, and adequate sleep) (Sirois, Kitner, & Hirsch, 2014). This study was a meta-analysis conducted over six years, and revealed a small effect of self-compassion on health behaviors, with a low variability. Additionally, results revealed indirect effects of self-compassion on health behaviors through positive affect.

Resilience & Motivation

While the research on self-compassion and health behavior is limited and has been conducted with samples from the general population, encouraging results have been found. Self-compassion has been positively related to increased motivation and effort for engaging in self-improvement activities, as well as increased belief that individuals can make beneficial changes in their own behavior (Breines & Chen, 2012; Magnus et al., 2010). Neff and colleagues (2005) examined academic achievement goals and coping with perceived failure. Results showed individuals who engaged self-compassion had greater mastery goals ($\beta = .28, p < .001$) versus performance goals, which was mediated by a

decreased fear of failure and a greater perceived competence ($\beta = .33, p < .001$) (Neff, Hsieh, & Dejjterat, 2005). Additionally, in Neff's proposed model, self-compassion was directly ($\beta = .15, p < .001$) and indirectly associated with intrinsic motivation, and partially mediated by mastery goals (Neff et al., 2005). Neff suggests that this may reflect the greater sense of autonomy and self-determination in more self-compassionate individuals, as previous research has shown (Neff, 2003; Neff et al., 2005).

Magnus and Kowalski (2010) explored the relationship between self-compassion and self-determined motives to exercise among young adult women, aged 17 to 43 years ($N = 252$), they found that individuals who are more self-compassionate are more prone to intrinsic motivation ($\beta = .18, p < .05$) in the exercise domain, and have lower levels of extrinsic or ego-related goal setting ($\beta = -.20, p < .05$) and social physical anxiety ($\beta = -.57, p < .05$) in exercise. Self-compassion has been shown to increase perceived well-being, self-efficacy, and social connectedness. In a study conducted by Smeets and colleagues (2014) examining the effectiveness of a three-week self-compassion intervention to increase resilience and wellbeing ($N = 52$) versus a control group, results showed that intervention significantly increased self-compassion ($F = 16.34, p < .01, d = 1.19$), optimism ($F = 4.98, p < .05, d = .66$), self-efficacy ($F = 3.25, p < .05, d = .52$), and connectedness ($F = 1.27, p < .05, d = .33$) (Smeets et al., 2014).

Another possible contributor to positive affect and engagement in health promoting behaviors is resilience. Resilience can be defined as, "positive adaptation in the face of stress or trauma" (Luthar, Cicchetti, & Becker, 2000). Resilience has been shown to contribute to positive health outcomes in individuals with disabilities (Kortte, Stevenson, Hosey, Castillo, & Weneger, 2012). In a qualitative study conducted by Monden (2014), focus groups were conducted with inpatients with a spinal cord injury at a rehabilitation hospital to gather information on how these individuals define resilience and what contributes to resilience for those with an acquired disability. Researchers

determined that social support and perspective contributed to resilience to adapting to a disability. Individuals described “perspective” similarly to the concept of mindfulness in the Self-Compassion Model wherein one steps back from the situation to see the experience as a whole rather than over-identifying (Monden et al., 2014). In Richardson’s Model of Resilience (2002), he identifies attributes or resilient qualities, including self-efficacy, social support, and self-esteem (which is similar to self-compassion). Based on Monden’s research and Richardson’s model of resiliency, resilience may be one factor that is influenced by self-compassion and mindfulness, and has the ability to impact relatedness, self-efficacy or competence, and motivation to engage in self-care behaviors after a traumatic event such as acquiring a disability (Monden et al., 2014; Richardson, 2002; White, Driver, & Warren, 2008).

Self-Compassion and Chronic Conditions/Disability

Self-compassion has been linked to improving individuals’ coping mechanisms related to life stressors such as chronic pain and disability (Costa & Pinto-Gouveia, 2011), increasing perceived well-being and quality of life, while also increasing health promoting behaviors such as exercising (Magnus et al., 2010). Self-compassion has also been shown to be a powerful moderator between physical health and quality of life (Allen, Goldwasser, & Leary, 2012). In addition, it has been demonstrated that improving feelings of acceptance may diminish the mental and emotional impact of living with a chronic disease, as well as contribute to a decrease in fatigue. For example, Allen and colleagues (2012) examined the role of self-compassion as a moderator between physical health and subjective well-being in the elderly ($N = 132$). This study found that in individuals with relatively good physical health, their perception of their subjective well-being was high regardless of their level of self-compassion ($t(127) = 6.35, p < .001, \beta = 0.49$). However, in participants with poorer physical health and disability, self-compassion was positively related to greater subjective well-being

($t(117) = 2.24, p < .027, \beta = .19$). Furthermore, the individuals who were more self-compassionate were more willing to use assistive devices such as mobility aides and hearing aides ($t(67) = 2.59, p < .012, \beta = .23$). This supports the idea that self-compassion plays a role in our perception of health and well-being.

Additionally, self-compassion has been associated with lower feelings of shame and embarrassment when experiencing a mobility disability (Terry & Leary, 2011). Because self-compassion involves showing oneself kindness and understanding during moments of suffering, understanding that pain and failure are part of the shared human experience and one is not alone, and promotes a balanced awareness of one's emotions (Neff et al., 2007), this construct can help individuals cope with health issues and life stressors, such as chronic disease, through treating themselves with kindness, keeping an objective mindset when viewing their situation, and seeing their challenges as part of the greater human experience, as opposed to an isolating event (Neff, 2003).

These findings have encouraging implications for use in populations with MS and other disabilities. Because individuals with MS face acute attacks, and often sudden worsening of symptoms and accumulation of disability, they endure greater psychological challenges and negative affect than the general population. Self-compassion is one construct that may help to re-shape how individuals with chronic conditions perceive their state of being and ability, and engage with health promoting behaviors.

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Appendix B: Questionnaire

Self-Compassion and Health Behaviors Survey

Thank you for your participation in this survey. Please answer all of the questions/statements independently and as truthfully as possible. Completion of this survey will help us understand how your self-compassion plays a role in engaging in health behaviors and improving your quality of life. If you have already completed this survey, please do not complete it again.

SECTION ONE: Self-Compassion Scale

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the right of each item, indicate how often you behave in the stated manner in relation to your Multiple Sclerosis, using the following scale:

	Almost Never	Rarely	Sometimes	Often	Almost Always
1. I'm disapproving and judgmental about my own flaws and inadequacies.	1	2	3	4	5
2. When I'm feeling down I tend to obsess and fixate on everything that's wrong.	1	2	3	4	5
3. When things are going badly for me, I see the difficulties as part of life that everyone goes through.	1	2	3	4	5
4. When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world.	1	2	3	4	5
5. I try to be loving towards myself when I'm feeling emotional pain.	1	2	3	4	5

6. When I fail at something important to me I become consumed by feelings of inadequacy.	1	2	3	4	5
7. When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am.	1	2	3	4	5
8. When times are really difficult, I tend to be tough on myself.	1	2	3	4	5
9. When something upsets me I try to keep my emotions in balance.	1	2	3	4	5
10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.	1	2	3	4	5
11. I'm intolerant and impatient towards those aspects of my personality I don't like.	1	2	3	4	5
12. When I'm going through a very hard time, I give myself the caring and tenderness I need.	1	2	3	4	5
13. When I'm feeling down, I tend to feel like most other people are probably happier than I am.	1	2	3	4	5
14. When something painful happens I try to take a balanced view of the situation.	1	2	3	4	5
15. I try to see my failings as part of the human condition.	1	2	3	4	5
16. When I see aspects of myself that I don't like, I get down on myself.	1	2	3	4	5
17. When I fail at something important to me I try to keep things in perspective.	1	2	3	4	5
18. When I'm really struggling, I tend to feel like other people must be having an easier time of it.	1	2	3	4	5
19. I'm kind to myself when I'm	1	2	3	4	5

experiencing suffering.					
20. When something upsets me I get carried away with my feelings.	1	2	3	4	5
21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.	1	2	3	4	5
22. When I'm feeling down I try to approach my feelings with curiosity and openness.	1	2	3	4	5
23. I'm tolerant of my own flaws and inadequacies.	1	2	3	4	5
24. When something painful happens I tend to blow the incident out of proportion.	1	2	3	4	5
25. When I fail at something that's important to me, I tend to feel alone in my failure.	1	2	3	4	5
26. I try to be understanding and patient towards those aspects of my personality I don't like.	1	2	3	4	5

SECTION TWO: Resilience Scale Revised

Please read each statement carefully before answering. To the left of each item, indicate how well each statement describes your feelings in relation to living with Multiple Sclerosis, using the following scale:

	Completely Disagree	Disagree	Neither Agree nor Disagree	Agree	Completely Agree
1. I am able to adapt to change	1	2	3	4	5
2. I can deal with whatever comes	1	2	3	4	5
3. I see the humorous side of things	1	2	3	4	5
4. I feel obligated to assist others in need	1	2	3	4	5
5. I tend to bounce	1	2	3	4	5

back after illness or hardship					
6. I can achieve my goals	1	2	3	4	5
7. Under pressure, I focus and think clearly	1	2	3	4	5
8. I am not easily discouraged by failure	1	2	3	4	5
9. I think of myself as a strong person	1	2	3	4	5
10. I can handle unpleasant feelings	1	2	3	4	5

SECTION THREE: Fatigue Severity Scale

Please read each question carefully. On the scale below, please indicate your agreement with each statement as it relates to how you have felt in the PAST 7 DAYS.

	Completely Disagree	Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Agree	Completely Agree
1. My motivation is lower when I am fatigued.	1	2	3	4	5	6	7
2. Exercise brings on my fatigue.	1	2	3	4	5	6	7
3. I am easily fatigued.	1	2	3	4	5	6	7
4. Fatigue interferes with my physical functioning.	1	2	3	4	5	6	7
5. Fatigue causes frequent problems for me.	1	2	3	4	5	6	7
6. My fatigue prevents sustained physical functioning.	1	2	3	4	5	6	7
7. Fatigue interferes with carrying out	1	2	3	4	5	6	7

certain duties and responsibilities.							
8. Fatigue is among my three most disabling symptoms.	1	2	3	4	5	6	7
9. Fatigue interferes with my work, family, or social life.	1	2	3	4	5	6	7

SECTION FOUR: Psychological Need Satisfaction in Exercise (PNSE) Scale

The following statements represent different feelings people have when they are physically active with Multiple Sclerosis. To the left of each item, please answer the following questions by considering how you typically feel while you are physically active, using the following scale:

	False	Mostly False	More false than true	More true than false	Mostly true	True
1. I feel that I am able to complete physical activities that are personally challenging	1	2	3	4	5	6
2. I feel free to exercise in my own way	1	2	3	4	5	6
3. I feel attached to my exercise companions because they accept me for who I am	1	2	3	4	5	6
4. I feel confident I can do even the most challenging physical activities	1	2	3	4	5	6
5. I feel free to make my own exercise program decisions	1	2	3	4	5	6
6. I feel like I share a common bond with people who are important to me when we exercise together	1	2	3	4	5	6
7. I feel confident in my ability to perform exercises that personally challenge me	1	2	3	4	5	6
8. I feel like I am in charge of my exercise program decisions	1	2	3	4	5	6
9. I feel a sense of camaraderie with my exercise companions because we exercise for the same reasons	1	2	3	4	5	6
10. I feel capable of completing physical	1	2	3	4	5	6

activities that are challenging to me						
11. I feel like I have a say in choosing the exercises that I do	1	2	3	4	5	6
12. I feel close to my exercise companions who appreciate how difficult exercise can be	1	2	3	4	5	6
13. I feel like I am capable of doing even the most challenging exercises	1	2	3	4	5	6
14. I feel free to choose which exercises I participate in	1	2	3	4	5	6
15. I feel connected to the people who I interact with while we exercise together	1	2	3	4	5	6
16. I feel good about the way I am able to complete challenging exercises	1	2	3	4	5	6
17. I feel like I am the one who decides what exercises I do	1	2	3	4	5	6
18. I feel like I get along well with other people who I interact with while we exercise together	1	2	3	4	5	6

SECTION FIVE: Leisure Time Physical Activity Questionnaire for People with Spinal Cord Injury (LTPAQ-SCI)

INSTRUCTIONS: This survey is asking you about the time you spent engaging in mild, moderate, and heavy intensity LTPA in the **last 7 days**. Leisure Time Physical Activity (LTPA) is physical activity that you choose to do during your free time, such as exercising, playing sports, gardening, and taking the dog for a walk (necessary physical activities such as physiotherapy, grocery shopping, pushing/wheeling for transportation are not considered LTPA). Please refer to the intensity chart on the following page for descriptions of what mild, moderate and heavy intensity LTPA feel like.

	During the <u>last 7 days</u> , on how many days did you do this type of LTPA?	On those days, how many minutes did you usually spend doing this type of LTPA?
1. Mild intensity LTPA requires very light physical effort; mild intensity activities make you feel like you are working a little bit, but you can keep doing _____ days _____ minutes them for a long time without getting tired.		

2. Moderate intensity

LTPA requires some physical effort; moderate intensity activities make you feel like you are working _____ days _____ minutes somewhat hard, but you can keep doing them for a while without getting tired

3. Heavy intensity LTPA

requires a lot of physical effort. Heavy intensity activities make you feel like you are working really hard, almost at your maximum. _____ days _____ minutes You cannot do these activities for very long without getting tired. These activities may be exhausting.

	Nothing at All	Mild	Moderate	Heavy
How hard are you working	Includes activities that even when you are doing them, you do not feel like you are working at all.	Includes physical activities that require you to do very light work. You should feel like you are working a little bit but overall you shouldn't find yourself working too hard	Includes physical activities that require some physical effort. You should feel like you are working somewhat hard but you should feel like you can keep going for a long time.	Includes physical activities that require a lot of physical effort. You should feel like you are working really hard (almost at your maximum) and can only do the activity for a short period of time
How does your body feel?				

Breathing & Heart Rate	Everything is normal	Stays normal or is only a little bit harder and/or faster than normal	Noticeably harder and faster than normal but <u>NOT</u> extremely hard or fast.	Fairly hard and much faster than normal.
Muscles		Feel loose, warmed up and relaxed. Not tired at all.	Feel pumped and worked. Feel warmer than normal and starting to get tired after a while.	Burn and feel tight and tense. Feel a lot warmer than normal and feel tired.
Skin		Normal temperature or is only a bit warmer and not sweaty.	A little bit warmer than normal and might be a little sweaty.	Much warmer than normal and might be sweaty.
Mind		You might feel very alert. Has no effect on concentration.	Requires some concentration to complete.	Requires a lot of concentration (almost full) to complete.

SECTION SIX: Function Neutral Health Related Quality of Life (FuNHRQoL) Short Form

On a scale of 1 to 7 (1 being never or almost never, and 7 being always or almost always), how would you rate the following questions:

During the last 4 weeks...	Never or Almost Never	Not Often	Occasionally	Sometimes	Often	Very Often	Always or Almost Always
1. Were you satisfied with your daily life in general?	1	2	3	4	5	6	7
2. Was your	1	2	3	4	5	6	7

overall emotional health good?							
3. Did you feel happy about your relationships with others?	1	2	3	4	5	6	7
4. Was your overall physical health good?	1	2	3	4	5	6	7
5. Were you happy about who you are?	1	2	3	4	5	6	7
6. Did you have sickness that interfered with your usual activities?	1	2	3	4	5	6	7
7. Did you feel that society valued you?	1	2	3	4	5	6	7
8. Did you experience physical pain?	1	2	3	4	5	6	7
9. Did your life have purpose?	1	2	3	4	5	6	7
10. Did you feel safe in the places that you live and go?	1	2	3	4	5	6	7
11. Did you feel depressed?	1	2	3	4	5	6	7
12. Did you get where you needed to go?	1	2	3	4	5	6	7
13. Did you feel important to your family or friends?	1	2	3	4	5	6	7

SECTION SEVEN: Demographic Form

Please check or write in the appropriate response.

1. What is your current age?
2. What is your gender?
☐ Male ☐ Male-to-female transgender (MTF) ☐ Do not want to answer
☐ Female ☐ Female-to-male transgender (FTM)
☐ Intersex ☐ Not listed
3. Which one of these groups would you say best represents your race/ethnicity?
☐ White ☐ Black or African American
☐ American Indian or Alaska Native ☐ Asian
☐ Pacific Islander ☐ Hispanic or Latino
☐ Not Listed ☐ Don't know/Not sure
☐ Do not wish to answer
4. What is your height in feet and inches?
5. What is your weight in pounds?
6. What year were you diagnosed with MS?
7. What type of MS do you have?
☐ Primary progressive ☐ Relapse-remitting
☐ Secondary progressive ☐ Progressive-relapsing

8. How long has it been since your last acute attack/relapse/exacerbation?

- ☐ < 3 months
- ☐ 4-6 months
- ☐ 7-9 months
- ☐ 10-12 months
- ☐ > 12 months

9. Are you currently...?

- ☐ Employed for wages
- ☐ Self-employed
- ☐ Out of work for 1 year or more
- ☐ Out of work for less than a year
- ☐ A homemaker
- ☐ A student
- ☐ Retired
- ☐ Unable to work

10. Are you...?

- | | |
|--|--|
| <input type="checkbox"/> Married | <input type="checkbox"/> Divorced |
| <input type="checkbox"/> Widowed | <input type="checkbox"/> Separated |
| <input type="checkbox"/> Never married | <input type="checkbox"/> A member of an unmarried couple |

11. Health Status: Would you say in general your health is:

- (1) excellent
- (2) very good
- (3) good
- (4) fair
- OR
- (5) poor

Appendix C: Recruitment Materials

<Date>

Hello!

Studies have shown that individuals with Multiple Sclerosis (MS) report some of the poorest health and engage in lower rates of physical activity than the general population. Research is needed to examine how to increase individual's physical activity to improve quality of life in this population. We are conducting a study to investigate the relationship of self-compassion on resilience, physical activity, and quality of life for individuals with MS.

We would like to invite you to participate in a survey to gather information about how self-compassion, suffering, resilience, physical activity behaviors, related to quality of life for individuals with MS. The survey takes approximately 20 to 30 minutes to complete. If you are between the ages of 18 and 65, can communicate in English, and have a medical diagnosis of MS, you are eligible to participate in this study. **Your answers will help improve our understanding of the process of self-compassion and physical activity on improving health-related quality of life for individuals with MS. Additionally, results from this study will help researchers develop effective health interventions to improve wellness and quality of life for people with MS.**

Participation in the study is voluntary, and all survey data will be deidentified. This research has been reviewed and approved by the Oregon State University Institutional Review Board (IRB) Office.

Within a week we will be sending you a survey packet. If you are eligible and would like to participate in the survey, please complete the survey packet and return the survey in the postage paid mailing envelope provided.

We appreciate your time and thank you for your assistance. If you have any questions regarding the survey, please contact Mara Nery at nerym@onid.oregonstate.edu or the principal investigator Joonkoo Yun at jk.yun@oregonstate.edu. If you have questions about your rights or welfare as a participant, please contact the Oregon State University Institutional Review Board (IRB) Office at (541) 737-8008 or by email at IRB@oregonstate.edu.

Sincerely,

Mara Nery
Exercise & Sport Science Program,
Movement Studies in Disability

Joonkoo Yun, PhD
Principal Investigator
Professor

School of Biological & Population Health Sciences
College of Public Health and Human Sciences
Oregon State University

Kinesiology Program,
Movement Studies in Disability
College of Public Health and Human Sciences
Oregon State University

Bcc email addresses:

Subject: Oregon State University Multiple Sclerosis Study

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Studies have shown that individuals with Multiple Sclerosis (MS) report some of the poorest health and engage in lower rates of physical activity than the general population. Research is needed to examine how to increase individual's physical activity to improve quality of life in this population. We are conducting a study to investigate the relationship of self-compassion on resilience, physical activity, and quality of life for individuals with MS.

We would like to invite you to participate in an online survey to gather information about how self-compassion, suffering, resilience, physical activity behaviors, related to quality or life for individuals with MS. The survey takes approximately 20 to 30 minutes to complete. If you are between the ages of 18 and 65, can communicate in English, and have a medical diagnosis of MS, you are eligible to participate in this study. **Your answers will help improve our understanding of the process of self-compassion and physical activity on improving health-related quality of life for individuals with MS. Additionally, results from this study will help researchers develop effective health interventions to improve wellness and quality of life for people with MS.**

Participation in the study is voluntary, and all survey data will be deidentified. This research has been reviewed and approved by the Oregon State University Institutional Review Board (IRB) Office.

If you are eligible and would like to participate in the survey, please follow this [link](#) to complete the survey.

We appreciate your time and thank you for your assistance. If you have any questions regarding the survey, please contact Mara Nery at nerym@onid.oregonstate.edu or the principal investigator Joonkoo Yun at jk.yun@oregonstate.edu. If you have questions about your rights or welfare as a participant, please contact the Oregon State University Institutional Review Board (IRB) Office at (541) 737-8008 or by email at IRB@oregonstate.edu.

Sincerely,

Mara Nery
Kinesiology Program,
Movement Studies in Disability
School of Biological & Population Health Sciences

Joonkoo Yun, PhD
Principal Investigator
Professor
Kinesiology Program,

College of Public Health and Human Sciences
Oregon State University
13 Women's Building, Corvallis, OR, 97331

Movement Studies in Disability
College of Public Health and Human Sciences
Oregon State University
202 Women's Building, Corvallis, OR, 9733

<Date>

Greetings!

We sent you a letter of invitation approximately seven days ago. We would like to invite you to participate in a survey to gather information about how self-compassion, suffering, resilience, and physical activity behavior relates to quality of life for individuals with MS. The survey takes approximately 20 to 30 minutes to complete. If you are between the ages of 18 and 65, can communicate in English, and have a medical diagnosis of MS, you are eligible to participate in this study. **Your answers will help improve our understanding of the process of self-compassion and physical activity on improving health-related quality of life for individuals with MS. Additionally, results from this study will help researchers develop effective health interventions to improve wellness and quality of life for people with MS.**

Participation in the study is voluntary, and all survey data will be deidentified. This research has been reviewed and approved by the Oregon State University Institutional Review Board (IRB) Office.

If you are eligible and would like to participate in the survey, please complete the attached survey packet and return the survey in the postage paid mailing envelope provided.

We appreciate your time and thank you for your assistance. If you have any questions regarding the survey, please contact Mara Nery at nerym@onid.oregonstate.edu or the principal investigator Joonkoo Yun at jk.yun@oregonstate.edu. If you have questions about your rights or welfare as a participant, please contact the Oregon State University Institutional Review Board (IRB) Office at (541) 737-8008 or by email at IRB@oregonstate.edu.

Sincerely,

Mara Nery

Joonkoo Yun, PhD

Kinesiology Program,
 Movement Studies in Disability
 School of Biological & Population Health Sciences
 College of Public Health and Human Sciences
 Oregon State University

Principal Investigator
 Professor
 Kinesiology Program,
 Movement Studies in Disability
 College of Public Health and Human Sciences
 Oregon State University

Bcc email addresses:

Subject: Oregon State University Multiple Sclerosis Study

Greetings!

We would like to invite you to participate in an online survey to gather information about how self-compassion, suffering, resilience, physical activity behaviors, related to quality or life for individuals with MS. The survey takes approximately 20 to 30 minutes to complete. If you are between the ages of 18 and 65, can communicate in English, and have a medical diagnosis of MS, you are eligible to participate in this study. **Your answers will help improve our understanding of the process of self-compassion and physical activity on improving health-related quality of life for individuals with MS. Additionally, results from this study will help researchers develop effective health interventions to improve wellness and quality of life for people with MS.**

Participation in the study is voluntary, and all survey data will be deidentified. This research has been reviewed and approved by the Oregon State University Institutional Review Board (IRB) Office.

If you are eligible and would like to participate in the survey, please follow this [link](#) to complete the survey.

We appreciate your time and thank you for your assistance. If you have any questions regarding the survey, please contact Mara Nery at nerym@onid.oregonstate.edu or the principal investigator Joonkoo Yun at jk.yun@oregonstate.edu. If you have questions about your rights or welfare as a participant, please contact the Oregon State University Institutional Review Board (IRB) Office at (541) 737-8008 or by email at IRB@oregonstate.edu.

Sincerely,

Mara Nery

Joonkoo Yun, PhD

Kinesiology Program,
 Movement Studies in Disability
 School of Biological & Population Health Sciences
 College of Public Health and Human Sciences
 Oregon State University

Principal Investigator
 Professor
 Kinesiology Program,
 Movement Studies in Disability
 College of Public Health and Human Sciences
 Oregon State University

Greetings!

We appreciate your time and thank you for your assistance in this research study. Your responses help us to understand how to effectively design programs that benefit individuals with MS by improving health and quality of life.

If you have any questions regarding the survey, please contact Mara Nery at nerym@onid.oregonstate.edu or the principal investigator Joonkoo Yun at jk.yun@oregonstate.edu. If you have questions about your rights or welfare as a participant, please contact the Oregon State University Institutional Review Board (IRB) Office at (541) 737-8008 or by email at IRB@oregonstate.edu.

Sincerely,

Mara Nery
 Kinesiology Program,
 Movement Studies in Disability
 School of Biological & Population Health Sciences
 College of Public Health and Human Sciences
 Oregon State University

Joonkoo Yun, PhD
 Principal Investigator
 Professor
 Kinesiology Program,
 Movement Studies in Disability
 College of Public Health and Human Sciences
 Oregon State University

Recruitment Advertisements



Participate in a Survey!



Examining self-compassion and health-related quality of life for individuals with Multiple Sclerosis

We would like to invite you to participate in a research study to understand how people with Multiple Sclerosis engage in physical activity and self-compassion, and how this impacts your quality of life. This survey is completely voluntary, and all survey data will be deidentified. The primary investigator for this study is Dr. Jk Yun.

This survey will help researchers create effective programs to help people with MS improve their health and wellness.

To complete the survey, follow the link:
http://oregonstate.qualtrics.com/SE/?SID=SV_bCnnbuAWCJwKTgF

If you have questions, please contact the research team at:
nerym@oregonstate.edu

PI: Joonkoo Yun



Participate in a Survey!

Examining self-compassion and health-related quality of life for individuals with Multiple Sclerosis

Studies have shown that individuals with Multiple Sclerosis (MS) report some of the poorest health and engage in lower rates of physical activity than the general population. Research is needed to examine how to increase individual's physical activity to improve quality of life in this population. We are conducting a study to investigate the relationship of self-compassion on resilience, physical activity, and quality of life for individuals with MS.

We would like to invite you to participate in an online survey to gather information about how self-compassion, suffering, resilience, physical activity behaviors, related to quality of life for individuals with MS.

- The survey takes approximately 20 to 30 minutes to complete.
- If you are between the ages of 18 and 65, can communicate in English, and have a medical diagnosis of MS, you are eligible to participate in this study.
- Participation in the survey is voluntary and all survey data will be deidentified

Your answers will help improve our understanding of the process of self-compassion and physical activity on improving health-related quality of life for individuals with MS. Additionally, results from this study will help researchers develop effective health interventions to improve wellness and quality of life for people with MS.

To complete the survey, go to this link:

http://oregonstate.qualtrics.com/SE/?SID=SV_8ktgzQ9Jki71UEt

IF YOU ARE INTERESTED OR HAVE ANY QUESTIONS:

Please contact the research team at:
nerym@onid.oregonstate.edu

Appendix D: Informed Consent

Explanation of Research

Project Title: Examining self-compassion and health-related quality of life for individuals with MS

Principal Investigator: Joonkoo Yun, PhD

Student Researcher: Mara Nery, MS

Version Date: 09/23/2015

Purpose: You are being asked to take part in a research study because you are an individual with Multiple Sclerosis. Individuals with Multiple Sclerosis (MS) face many unique and unpredictable health challenges, and often participate in less physical activity and experience poorer quality of life than the general population. Health professionals are challenged to find ways to help individuals manage MS and promote health and wellness. One method of improving health and decreasing suffering is actively engaging in self-compassion. Self-compassion has been linked to engagement in physical activity and exercise, improving positive feelings and quality of life, and decreasing anxiety, depression, and stress.

The purpose of this study is to improve our knowledge about suffering, self-compassion, health behavior, and wellness for individuals with MS. Your responses will help researchers develop effective health interventions to improve the health and wellness of individuals living with MS. This study is intended for a doctoral degree dissertation for the student investigator, presentation at professional meetings, and publication in research journals.

Activities: If you decide that you want to participate in this study, we will ask you to fully complete the questionnaires to the best of your knowledge. The questionnaires will ask you about your self-compassion, resilience, physical activity, psychological needs, suffering, and quality of life with MS.

Time: Your participation in this study will last about 20 to 30 minutes.

Risks: There are no foreseeable risks to participating in this study.

Benefit: There may be no benefits to participating in the survey. However, the results from the surveys will be used to develop health interventions for individuals with MS to increase wellness and quality of life.

Payment: You will not be paid for being in this research study.

Confidentiality: Your participation in this study is anonymous.

Voluntary: Participation in this study is voluntary. If you choose to participate, you are free to skip any questions that you would prefer not to answer.

Study contacts: If you have any questions about this research project, please contact: Joonkoo Yun at jk.yun@oregonstate.edu or by phone (541) 737-6613. If you have questions about your rights or welfare as a participant, please contact the Oregon State University Institutional Review Board (IRB) Office, at (541) 737-8008 or by email at IRB@oregonstate.edu

Agreement: Completing the questionnaires indicates that this research study has been explained to you through the above “explanation of research” document, and that you agree to take part in this study, which is described above. You may keep this form for your records.

You meet the inclusion requirements for this study if you:

- (1) Have a medical diagnosis of Multiple Sclerosis
- (2) Are between the ages of 18 and 65

If you meet these requirements and would like to participate in this study, please continue to the questionnaire.

Explanation of Research

Project Title: Examining self-compassion and health-related quality of life for individuals with MS

Principal Investigator: Joonkoo Yun, PhD

Student Researcher: Mara Nery

Version Date: 09/23/2015

Purpose: You are being asked to take part in a research study because you are an individual with Multiple Sclerosis. Individuals with Multiple Sclerosis (MS) face many unique and unpredictable health challenges, and often participate in less physical activity and experience poorer quality of life than the general population. Health professionals are challenged to find ways to help individuals manage MS and promote health and wellness. One method of improving health and decreasing suffering is actively engaging in self-compassion. Self-compassion has been linked to engagement in physical activity and exercise, improving positive feelings and quality of life, and decreasing anxiety, depression, and stress.

The purpose of this study is to improve our knowledge about suffering, self-compassion, health behavior, and wellness for individuals with MS. Your responses will help researchers develop effective health interventions to improve the health and wellness of individuals living with MS. This study is being conducted for the completion of a doctoral dissertation.

Activities: If you decide that you want to participate in this study, we will ask you to fully complete the questionnaires to the best of your knowledge. The questionnaires will ask you about your self-compassion, resilience, physical activity, psychological needs, suffering, and quality of life with MS.

Time: Your participation in this study will last about 20 to 30 minutes.

Risks: There are no foreseeable risks to participating in this study. However, the security and confidentiality of information collected from you online cannot be guaranteed. Confidentiality will be kept to the extent permitted by the technology being used. Information collected online can be intercepted, corrupted, lost, destroyed, arrive late or incomplete, or contain viruses.

Benefit: There may be no benefits to participating in the survey. However, the results from the surveys will be used to develop health interventions for individuals with MS to increase wellness and quality of life.

Payment: You will not be paid for being in this research study.


Confidentiality: Your participation in this study is anonymous.

Voluntary: Participation in this study is voluntary. If you choose to participate, you are free to skip any questions that you would prefer not to answer.

Study contacts: If you have any questions about this research project, please contact: Joonkoo Yun at jk.yun@oregonstate.edu or by phone (541) 737-6613. If you have questions about your rights or welfare as a participant, please contact the Oregon State University Institutional Review Board (IRB) Office, at (541) 737-8008 or by email at IRB@oregonstate.edu

Agreement: Completing the questionnaires indicates that this research study has been explained to you through the above “explanation of research” form, and by clicking **NEXT** you are agreeing to take part in this study, which is described above.

If you would like to participate in this study, please click **NEXT** to continue to the survey.




Are you between the ages of 18 and 65?

☐ Yes

☐ No

0% 100%

Survey Powered By [Qualtrics](#) >>



Do you have a medical diagnosis of Multiple Sclerosis?

☐ Yes

☐ No

0% 100%

<< >>

Survey Powered By [Qualtrics](#)

Appendix E: Institutional Review Board Approval

**EXEMPT
DETERMINATION**

Date of Notification	10/27/2015		
Study ID	7057		
Study Title	Examining self-compassion and health-related quality of life for individuals with MS		
Principal Investigator	JoonKoo Yun		
Study Team Members	Mara Nery		
Submission Type	Project Revision	Date Acknowledged	10/26/2015
Level	Exempt	Category(ies)	2
Funding Source	None	Proposal #	N/A
PI on Grant or Contract	N/A	Cayuse #	N/A

The above referenced study was reviewed by the OSU Institutional Review Board (IRB) and determined to be exempt from full board review.

EXPIRATION DATE: 09/23/2020

The exemption is valid for 5 years from the date of approval.

Annual renewals are not required. If the research extends beyond the expiration date, the Investigator must request a new exemption. Investigators should submit a final report to the IRB if the project is completed prior to the 5 year term.

Documents included in this review:

- | | | |
|---|--|--|
| <input checked="" type="checkbox"/> Protocol | <input type="checkbox"/> Recruiting tools | <input type="checkbox"/> External IRB approvals |
| <input checked="" type="checkbox"/> Consent forms | <input checked="" type="checkbox"/> Test instruments | <input type="checkbox"/> Translated documents |
| <input type="checkbox"/> Assent forms | <input type="checkbox"/> Attachment A: Radiation | <input type="checkbox"/> Attachment B: Human materials |
| <input type="checkbox"/> Alternative consent | <input type="checkbox"/> Alternative assent | <input type="checkbox"/> Other: |
| <input type="checkbox"/> Letters of support | <input type="checkbox"/> Grant/contract | |

Comments: Revision to shorten the length of the test instrument in order to reduce participants' time commitment; revision to the formatting of the mailed consent form.

Principal Investigator responsibilities:

- Certain amendments to this study must be submitted to the IRB for review prior to initiating the change. These amendments may include, but are not limited to, changes in funding, , study population, study instruments, consent documents, recruitment material, sites of research, etc. For more information about the types of changes that require submission of a project revision to the IRB, please see:
http://oregonstate.edu/research/irb/sites/default/files/website_guidancedocuments.pdf
- All study team members should be kept informed of the status of the research. The Principal Investigator is responsible for ensuring that all study team members have completed the online ethics training requirement, even if they do not need to be added to the study team via project revision.
- Reports of unanticipated problems involving risks to participants or others must be submitted to the IRB within three calendar days.

