AN EXAMINATION OF EMOTION REGULATION AND HEALTH-RELATED QUALITY OF LIFE IN PATIENTS WITH MULTIPLE SCLEROSIS

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This dissertation is dedicated to my loving parents,

Dr. Gary & Mrs. Cathy Tarrant.

Abstract

Background: Multiple Sclerosis (MS) is a chronic, and unpredictable, neurodegenerative disease of the central nervous system (CNS). Due to the unpredictability of the disease, and diversity of symptoms, an individual's perspective of their overall health and well-being may change with an MS diagnosis, labelled health-related quality of life (HRQOL). A reported symptom of MS is emotion dysregulation. Emotion regulation refers to the ability to initiate, inhibit or modulate the occurrence, intensity or duration of feelings. There is limited research to allow clinicians and patients to fully understand the relationship between emotion regulation and HRQOL among patients with MS. **Objective:** The goal of the present study is to gain a better understanding of the role of emotion regulation in HRQOL among Canadian patients with MS. Specifically, this study aimed to determine if emotion regulation, and its associated constructs, could predict mental and physical HRQOL after controlling for age, gender, and social support. **Method:** Adults diagnosed with MS participated in this cross-sectional study. Self-report data was collected from June 2015 - April 2018 through online and mail-out survey methods following recruitment using social media and neurology clinic referrals. The Difficulties in Emotion Regulation Scale (DERS), Short Form-12 Health Survey (SF-12 HS), and a sociodemographic questionnaire were used to collect information on variables of interest. Missing data was handled using multiple imputation. Correlations and hierarchical regressions were performed to determine the predictive value of emotion regulation and its multifaceted constructs (i.e., goals, impulsivity, strategies, clarity, awareness, and non-acceptance) on HRQOL among those with MS. **Results:** The final sample consisted of 54 participants with MS. Pearson correlation revealed that mental health related quality of life (MHRQOL), but not physical-

health related quality of life (PHRQOL), significantly decreased as emotion dysregulation increased. Hierarchical multiple regression revealed that emotion regulation predicated MHRQOL over and above age, gender, and social support, with the construct of goal-directed behaviour driving this association. **Discussion:** The current study provides support that emotion regulation, with a particular focus on goal-directed behaviour, is related to MHRQOL, over and above age, gender and social support. This study did not find the same association between emotion regulation and PHRQOL. The results of the current study highlight the importance of psycho-social intervention that targets emotion regulation in those with MS. Future directions for research might include complementary qualitative analysis of experiences of emotion dysregulation in patients with MS.

Keywords: Multiple Sclerosis, health-related quality of life, emotion regulation

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List of Abbreviations

Abbreviation	Definition
CIS	Clinically Isolated Syndrome
CNS	Central Nervous System
CSF	Cerebral Spinal Fluid
DERS	Difficulties in Emotion Regulation Scale
EBV	Epstein Barr Virus
EPM	Extended Process Model
HRQOL	Health Related Quality of Life
MHC	Major Histocompatibility Complex
MHRQOL	Mental Health Related Quality of Life
MOS SF-36	Medical Outcomes Study 36-item Health Survey
MRI	Magnetic Resonance Imaging
MS	Multiple Sclerosis
PHRQOL	Physical Health Related Quality of Life
PPMS	Primary Progressive Multiple Sclerosis
PRMS	Progressive Relapsing Multiple Sclerosis
RIS	Radiologically Isolated Syndrome
RRMS	Relapse-Remitting Multiple Sclerosis
SF-12 HS	Short Form-12 Health Survey
SPMS	Secondary Progressive Multiple Sclerosis
SPSS	Statistical Package for the Social Sciences

Chapter 1: Introduction

Multiple Sclerosis (MS) is a chronic, unpredictable, neurodegenerative disease of the central nervous system (CNS). The exact etiology of MS is unknown; however, research supports that both environmental and genetic factors play a role in its onset (Sadovnik, 2019). MS affects individuals of all ages and walks of life, with females being two to three times more likely to be diagnosed with the disease (Marrie et al., 2013; Amankwah et al., 2017). The disease is primarily diagnosed in adults aged 20-50 years, and is one of the leading causes of neurological disability in young adults (Browne et al., 2014). The prevalence of MS in Canada is one of the highest in the world, with Atlantic Canada being most impacted (Beck et al., 2005; Poppe et al., 2008).

It is broadly accepted that MS occurs due to an autoimmune response in which the myelin of the CNS is targeted (Compston & Coles, 2008). Myelin is diffuse across the CNS, and subsequently the brain injury acquired is also diffuse, reflecting the diverse symptoms experienced by those with MS. Symptoms of the disease, such as fatigue, muscle weakness, visual acuity loss, and motor impairment, are often debilitating and vary in severity between patients (Ömerhoca et al., 2018; Silveira et al., 2019). Additionally, many 'invisible' cognitive and affective symptoms, such as mental health challenges, co-occur with physical symptoms (Davis et al., 2021). A review of the neuropsychiatric conditions found in those with MS by Silviera et al. (2019), indicated that depressive, anxiety symptoms, psychotic disorder, bipolar disorder, substance use, and other affect abnormalities (e.g., pseudo-bulbar affect) were more prevalent in those diagnosed with MS compared to the general population. For example, a systematic review of psychiatric conditions in those with MS reported a prevalence of 23.7% for depression,

21.9% for anxiety, 4.3% for psychosis, 5.8% for bipolar disorder, and 14.8% for alcohol abuse (Marrie et al., 2015a). Additionally, comparison of psychiatric conditions of those with MS to an age, sex, and geographically matched general population control group found that the incidence and prevalence rates of all psychiatric conditions were higher in those with MS, compared to the general population (Marrie et al., 2015b).

The impact of having MS in young adulthood is negative and pervasive as the identity-forming years of life are disrupted by both the symptoms and the uncertainty of the disease progression. As both physical and psychological functioning are affected, it is not surprising that an individual's perspective of their overall health and well-being may change (Visser et al., 2021). This perspective is commonly referred to as health-related quality of life (HRQOL) and is used broadly in clinical research to assess clinical intervention effectiveness (Kuspinar et al., 2012). Patients with MS have been identified as experiencing worse HRQOL compared to the general population (Goodwin et al., 2020; McCabe & McKern, 2002. Amtmann et al., (2017) found that scores on all health domains measured (e.g., physical function, pain interference, fatigue, sleep-disturbance, etc.), were worse by half a standard deviation or more for those with MS. Furthermore, HRQOL of patients diagnosed with MS has been found to be worse than the HRQOL of patients with other chronic conditions, such as diabetes, epilepsy, inflammatory bowel disease, and rheumatoid arthritis (Hermann et al., 1996; Rudick et al., 1992). Previous research which examines the HRQOL of people with MS compared to the HRQOL of people with other chronic conditions is sparse, underscoring the importance of better understanding the construct of HRQOL in those with chronic conditions. Interestingly, several factors have been identified as impactful to HRQOL in folks with MS, including

age, sex, and social support (Yamout et al., 2013; Sabanagic-Hajric et al., 2022). Social support in particular has been found to be of high importance, with Costa and colleagues (2012) reporting that support along with age explained 23.1% of the variance in physical function. More recently it was found that perceived social support was a significant predictor of HRQOL accounting for between 41-47% of the variance in HRQOL in a sample of 151 individuals with MS (Eizaguirre et al., 2023).

One area that has shown some promise in better understanding the HRQOL of those with MS is emotion regulation. Emotion regulation refers to the ability to initiate, inhibit or modulate the occurrence, intensity or duration of positive and negative feeling, and has been documented as an area of primary concern for those with MS (Eisenberg & Spinrad, 2004; Harel et al., 2007). Phillips et al. (2014) found that patients with MS (n=31) self-reported significantly more difficulty with emotion regulation compared to healthy-control participants, independent of executive dysfunction. Additionally, they reported that difficulty with emotion regulation predicted poor quality of life within social, psychological, and environmental domains (Phillips et al., 2014). There is limited research explaining the relationship between emotion regulation and HRQOL despite emotion regulation being a key component in both mental health and adaptive functioning.

The aim of the current research is three-fold: 1) to explore the sociodemographic and clinical characteristics of Canadians with MS; 2) to determine if emotion regulation is significantly associated with the physical and mental HRQOL among patients with MS; and 3) to determine if emotion regulation significantly predicts physical and mental HRQOL over and above age, gender, and social support among those with MS.

Chapter 2: Review of Literature

2.1 Heterogeneity of Multiple Sclerosis

While the exact cause remains unknown, Multiple Sclerosis (MS) has been shown to present in multiple members of the same family, indicating a possible genetic or environmental link (Schapira et al., 1963). Despite this identification of familial clustering of MS many decades ago, there has been no identified single theory of nature or nurture that explains the disease. Rather, research findings suggest that the cause of MS is multi-faceted, with complex interactions between an individual's genes and their environment resulting in disease presentation (Sadovnik, 2019).

The first reported genetic finding associated with MS was the antigen HLA-A3 found in the major histocompatibility complex (MHC) (Bertrams et al., 1972). However, the understanding of the genetic architecture of MS continues to evolve parallel with the ever-expansive knowledge of the genome. In 2011, following a large genome-wide meta-analysis, more than a dozen susceptibility loci for MS were identified in addition to the previously identified associations between genes found in the MHC (Patsopoulous et al., 2011). Less than a decade later, more than 200 non-MHC genome-wide associations have been identified in relation to MS (Madireddy et al., 2019; Cotsapas & Mitrovic, 2018). A meta-analysis of twin studies completed by Fagnani et al. (2015) found that heritability accounted for half of the total variance of MS development. The heritability of MS indicates that there is a genetic component that is contributing to the development of the disease among certain individuals, with the genetic component potentially having implications for diagnosis and timely intervention. Additionally, having family members with the disease may allow for a better understanding of MS and its management at the

individual and familial level. However, it also may negatively impact the quantity and quality of social support available, given the potential for increased caregiver burden within a family unit.

There have been several environmental factors associated with a higher likelihood of developing MS. A meta-analysis completed by Degelman & Herman (2017) concluded that there was strong evidence that smoking plays a causal role in MS risk (OR/RR 1.54, 95% CI [1.46–1.63]), and moderate evidence that smoking plays a causal role in MS progression (HR 1.13, 95% CI [0.73–1.76]. An additional factor that has been identified in the desire to understand the etiology of MS is the Epstein-Barr Virus (EBV) (Ascherio & Munger, 2007). While the mechanism through which EBV influences MS remains unknown, it has been shown to increase MS risk, specifically for individuals who have previously contracted infectious mononucleosis because of EBV (Jacobs et al., 2020). Additionally, EBV was noted to interact with smoking, with those individuals who smoked being more at-risk of MS only if they presented with high anti-EBV antibodies (Jacobs et al., 2020). Another possible environmental factor identified as influential in MS risk is vitamin D deficiency (Ascherio & Munger, 2007; Sintzel et al., 2018). Higher levels of vitamin D have been associated with reduced risk and progression of MS (Munger et al., 2006; Munger & Ascherio, 2011). Interestingly, it is thought that vitamin D deficiency might explain why there is a distinct geographical distribution of MS, with incidence and prevalence increasing with latitude from the equator (Ascherio & Munger, 2007). For adults that migrate from a low-incidence to a high-incidence geographic location, there appears to be a long-lasting protective factor, which decreases their MS risk (Dean et al., 1976; Elian et al., 1990). Conversely, adults who migrate from high-

incidence to low-incidence geographic locations, appear to decrease their risk of MS (Kurtzke et al., 1985). The etiology of MS continues to be researched, with more recent studies investigating possible contributing factors such as epsilon toxin, metallic elements in the blood, and nano-bacteria (Wagley et al., 2018; De Oliveira et al., 2020; Can Demirdöğen, 2019).

Biologically, it is widely accepted that MS occurs due to a targeted auto-immune response in which the myelin and axons of the central nervous system (CNS) are attacked by the body's immune system (Compston & Coles, 2008). Myelin is the fatty tissue which insulates nerves and allows signals to travel quickly and efficiently between neurons and it is diffuse across the CNS, with myelin being found in the brain, spinal cord, and optic nerve. The brain injury acquired from MS presents as scattered demyelinated lesions of the CNS, reflective of the diverse symptoms found across diagnosed individuals (Housley et al., 2015). Common symptoms of MS include cognitive (e.g., deficits in executive function), emotional (e.g., increased lability, depressive symptoms), and physical (e.g., tremors, vision changes, spasticity, pain) changes that may be exacerbated by core body temperature increase (Compston & Coles, 2008; Silveira et al., 2019). MS is the leading cause of neurological disability in young and middle-aged adults in Canada, with most individuals diagnosed during the identity-forming years of life (Browne et al., 2014). In a review of two Canadian MS cohorts, Kingwell et al. (2010) identified the mean age of disease onset for both groups (n=7194) to be in their early thirties.

There have been several diagnostic guidelines and subsequent revisions used for the identification of clinically definite MS. Recognizing the need for patients and

clinicians to effectively communicate disease course, the first formal classification of MS phenotype was quickly integrated into clinical practice and research, and included: Primary Progressive (PPMS; i.e., continuous worsening of symptoms starting at onset), Relapsing-Remitting (RRMS; i.e., time-period of symptoms, followed by time period where symptoms remit), Secondary Progressive (SPMS; i.e., at onset the symptoms follow a relapse-remitting course, which then changes to continuous worsening of symptoms) and Progressive Relapsing (PRMS; i.e., continuous worsening of symptoms with time periods of relapse) (Lublin & Reingold, 1996). Since these formal classifications were first developed, PRMS subtype has been absorbed into the PPMS classification, eliminating the diagnostic label (Lublin et al., 2014). Additionally, Lublin et al. (2014) identified two other courses of significance including Clinically Isolated Syndrome (CIS; first episode of symptoms that could indicate MS should demyelination continue) and Radiologically Isolated Syndrome (RIS; MRI abnormalities reflective of demyelination without accompanied symptoms). While RIS is not considered a distinct phenotype of MS, it has garnered some clinical interest, with many patients diagnosed with RIS going on to develop CIS within five years (Lebrun et al., 2009; Okuda et al., 2009). CIS, while considered a distinct recognized disease course, is a provisional diagnosis in nature, with follow-up required to ascertain if an individual develops clinically definite MS (Klineova & Lublin, 2018). Additionally, since the advent of the 2013 classification system of MS course, additional specifiers such as: Active, Not Active, With Progression, Without Progression, Worsening, and Stable are used to better understand an individual's symptom manifestation (Lublin et al., 2014).

The continual evolution of increasingly refined criteria reflects advances in diagnostic tools (e.g., magnetic resonance imaging (MRI), cerebral spinal fluid (CSF) measurement) (Klineova & Lublin, 2018). Currently, the most widely used clinical criteria in the diagnosis of MS are the McDonald criteria, with the most recent revisions developed in 2017 (Thompson et al., 2018). The McDonald criteria stipulate that an individual must present with evidence of dissemination of lesions in the CNS across space and time, with no other likely differential diagnoses, in order to be diagnosed with MS (Thompson et al., 2018). Clinical definite MS would require an individual to present clinically with two symptom attacks, and two identifiable lesions. Given that MS patients are often subject to diagnostic delay (decreasing timely and appropriate care), the 2017 revisions have more thoroughly integrated MRI and CSF level results to supplement previous avenues of diagnosis (Thompson et al., 2018).

There is a vast difference in the length of disease duration due to the highly heterogeneous nature of the disease course and legions of brain injury. Often patients with RRMS fare better than those with PPMS, with shorter disease duration, less disability and fewer lesions (Giovannoni, 2004). Additionally, the difference in disease course can translate into prognosis, with patients diagnosed as having RRMS presenting with a lower risk of disability progression at 10-year follow up, and earlier onset of disease predictive of worse prognosis (Kerbrat et al., 2015; Ozakbas et al., 2012). Despite these general findings, due to the heterogeneity of the disease, no accurate and applicable prognostic model has been successfully developed (Pellegrini et al., 2020).

2.2 Health-Related Quality of Life

Given the uncertain disease course and prognosis of MS, it is not surprising that an individual's perspective of their overall health and well-being will change with the diagnosis. This perspective is commonly labelled health-related quality of life (HRQOL), and is used broadly in clinical research to assess clinical intervention effectiveness (Kuspinar et al., 2012). Within much of research, HRQOL is subdivided into mental and physical health components. This is reflective of medical care practice, where despite the bidirectional influence, mental health and physical health tend to be disconnected in terms of the categorization of health behaviours and provision of services (Forstmann et al., 2012). However, a growing body of research has continued to highlight mind-body connections, with factors related to healthy body (e.g., exercise, balanced diet) positively impacting the mind, and factors related to healthy mind (e.g., executive functioning, healthy expression of emotion) positively impacting the body (Wu et al., 2019; Ezra et al., 2019). As such, while physical and mental HRQOL continue to be subdivided into their separate categories for the purposes of clinical measurement, it is important that both physical and mental HRQOL be examined in relation to emotion regulation to better understand the connection between body and mind health states.

While it is natural to want a parsimonious explanation for an individual's perceived level of well-being, HRQOL is better conceptualized by the interaction between dynamic and stable factors of individual, environmental, and disease characteristics (Wilson & Cleary, 1995). In 1995, Wilson and Cleary proposed a multi-dimensional model for HRQOL, which integrated bio-medical factors and psycho-social factors. The Wilson and Clearly model described five facets of health that are commonly measured by health researchers which they ordered on a continuum from biologically

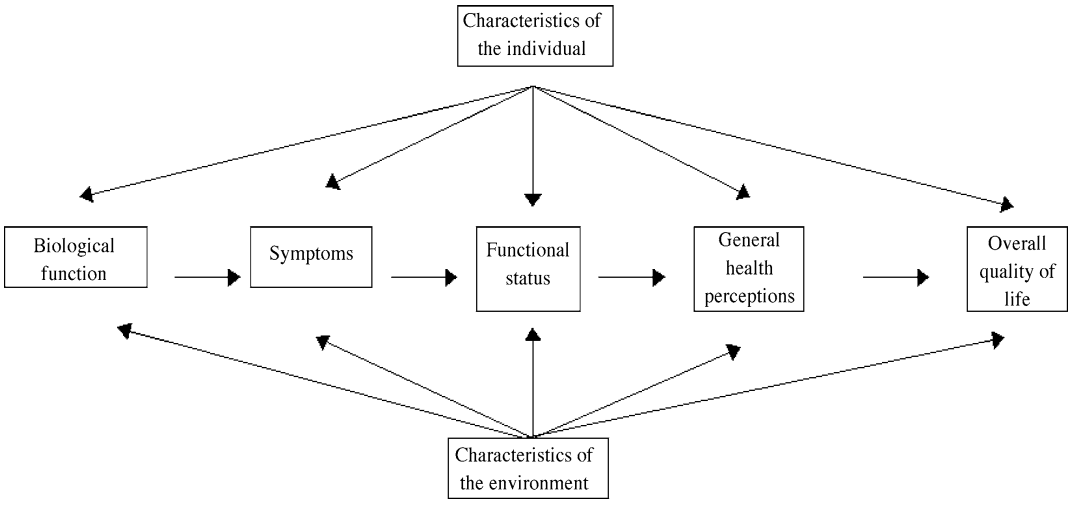
specific to integrated complex facets. The five facets include: (1) biological function (e.g., function of cells, organs, genes); (2) psychological and physical symptoms as perceived by the patient (e.g., depressed mood, tremors, sleep disturbance); (3) functional status (e.g., adaptive behaviours); (4) general health perceptions (i.e., the subjective rating of preceding factors); and (5) overall quality of life (i.e., subjective satisfaction with life). Individual and environmental characteristics were described as having an influence on four of the five facets, excluding biological function. The final facet (i.e., overall quality of life) was also noted to be influenced by non-medical factors, while the fourth facet (i.e., general health perceptions) would be best conceptualized as HRQOL. This model has been widely used in health research to generate and test hypotheses with many chronic conditions such as stroke, HIV/AIDS, and generalized anxiety disorder (Mayo et al., 2015; Nokes et al., 2011; Wyrwich et al., 2011).

While other conceptual models of HRQOL have been proposed, such as World Health Organization's Classification of Functioning, Disability, and Health (2007), a systematic review of the three most applied HRQOL models, completed by Bakas et al. (2012), reported that Ferrans et al.'s revision of the Wilson and Cleary model appeared to have the greatest potential to guide research and practice due to its comprehensiveness and clarity. Ferrans, Zerwic, Wilbur, and Larson (2005) revised the Wilson and Cleary conceptual model of HRQOL, to provide increased clarity surrounding the importance of individual and environmental factors. The revised model includes the five facets of health that were included in the original model (i.e., biological function, symptoms as perceived by patient, functional status, general health perceptions, and overall quality of life) (Wilson & Cleary, 1995; Ferrans et al., 2005). However, it places increased emphasis on

individual and environmental factors that interact bi-directionally with each of the five facets. Additionally, the revised model removed non-medical factors as they were thought to be captured more holistically within individual and environmental characteristics. Individual characteristics include demographic, developmental, psychological, and biological factors, while environmental characteristics include social or physical factors (Eyler et al., 2002; McLeroy et al., 1998). While demographic (e.g., age, sex), developmental (e.g., life-stage, cognitive level), and biological (e.g., body-mass index, skin colour) factors are stable, psychological factors (e.g., cognitive, affective, and motivation) were identified as malleable, and a possible target for intervention (Ferrans et al., 2005).

Figure 1

Revised Wilson & Cleary Model for Health-Related Quality of Life.



Note. Obtained from "Conceptual Model of Health-Related Quality of Life," by C.E. Ferrans, J.J. Zerwic, J.E. Wilbur & J.L. Larson. Copyright 2005 by John Wiley and Sons. Used with Permission.

Currently, limited research examining patients with MS has been completed using the Ferrans et al. conceptual model of HRQOL as a framework to drive hypothesis testing. However, several studies have used Ferrans et al.'s revised model with other chronic conditions, such as Parkinson's Disease, Acquired Brain Injury, and HIV/AIDS (Chekani et al., 2016; Connell et al., 2018; Alsayed et al., 2017). For example, Alsayed et al. (2017) examined the relations of the five central facets of HRQOL as well as environmental and individual characteristics in women living with HIV/AIDS and found that women with lower depressive symptoms, lower HIV-related stigma, higher support, higher physical functioning, and higher general health had increased HRQOL. An examination of nursing home residents (n=98 093) with Parkinson's Disease found that individual, environmental, and biological factors were associated with functional status and subsequent HRQOL (Chekani et al., 2016). In 2021, Duangchan and Matthews completed a systematic review of 31 studies from 2005-2020 which utilized Ferrans et al.'s conceptual model of HRQOL and determined the model to be popular in informing research. All twenty hypothesized associations between individual, environmental, and the five facets of HRQOL, were identified as having been tested within the literature with all 20 associations, excluding that of environmental characteristics and biological function, being supported by study results. However, it was advised that additional research be undertaken to gain a more robust understanding of these associations (Duangchan & Matthews, 2021).

While limited studies using the Ferrans et al. conceptual model of HRQOL have been completed with patients diagnosed with MS, generally, patients with MS have been

identified as experiencing poorer HRQOL when compared to both the general population and patients with other chronic conditions, such as rheumatoid arthritis and inflammatory bowel disease (Miller & Dishon, 2006; Hincapie-Zapata et al., 2009; Campbell et al., 2013). It is therefore paramount that clinicians understand and identify the factors that are negatively influencing HRQOL in those with MS, to provide effective targeted intervention. Thankfully, many influential factors have already been identified, such as those related to environmental characteristics of social support and access to exercise programming (Motl et al., 2013; Costa et al., 2012). Additionally, disease-specific factors (e.g., symptoms, level of disability, treatments) have also been found to be instrumental in an individual's perception of their own health and well-being (Bužgová et al., 2020; Jongen, 2017). Static individual characteristics related to demographics (e.g., age) and biology (e.g., sensory processing) have also been identified as factors affecting HRQOL among those with MS (Stern et al., 2020; Baumstarck et al., 2015). For example, Baumstarck and colleagues found that longer disease course and higher age resulted in worse reported QOL in those with RRMS (2015). Additionally, male gender has been found to be associated with worse reported HRQOL in many studies– potentially linked to their higher likelihood of PPMS, while female gender has been found to be associated with worse HRQOL in some research (Coyle et al., 2021; Stern et al., 2020). However, the identification of static individual characteristics does not provide a pathway to direct intervention despite having utility to help triage the provision of services to those who might be at highest risk for poor HRQOL.

Recent research has shifted to examine more dynamic cognitive, affective, and motivational factors to determine potential pathways for directed intervention. For

example, Gedik (2020), found that poor self-esteem and lack of self-compassion contributed to significantly lower HRQOL among patients with MS. This leads to a promising avenue for targeted intervention given that self-compassion and self-esteem are modifiable psychological constructs. While certain individual characteristics such as temperament and personality can be quite rigid in response to intervention, more dynamic constructs such as emotion regulation have been found to be amenable to intervention in other cognitively impacted populations such as those with traumatic brain injury and autism spectrum disorder (Tsaousides et al., 2017; White et al., 2021).

2.3 Emotion Regulation

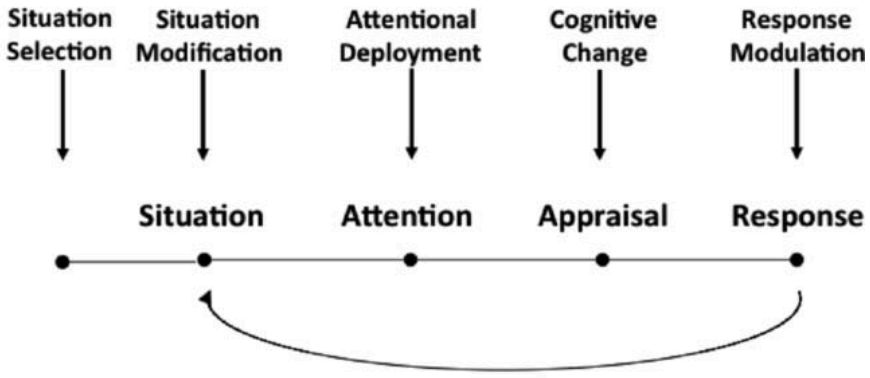
One possible factor that could impact HRQOL is emotion regulation. To regulate emotion, one first needs to have the ability to generate emotions, followed by an awareness of emotional response, and the desire to change the experienced emotion in some way. Emotion is defined as a negative or positive subjective affective state, specific to a certain situation, often prompting a physiological and behavioural response (Lazarus, 1993; Gross, 2014). Emotion is not to be confused with stress, a whole-body physiological reaction, or with mood, a longer lasting general affective state across situations (Gross, 2014). One way that the generation of emotion has been theoretically understood, is through the Modal-Model of emotion. The Modal-Model postulates that the experience of emotion occurs in four major steps, including: (1) situation, (2) attention, (3) appraisal, and (4) response (Gross, 2014). The first step, situation, refers to any internal or external experience that is psychologically relevant to the individual (i.e., short-term or long-term goals, self-concept, safety). Following a situation that is psychologically relevant, it likely that an individual will attend the situation. This will

naturally result in the appraisal of the situation as is relevant to that person and their goals. A response in relation to their appraisal of the situation will in turn change the situation, and begin a whole new cycle of emotion generation (Gross, 2014).

Emotion regulation refers to the ability to initiate, inhibit or modulate the occurrence, intensity, or duration of positive and negative emotion (Eisenberg & Spinrad, 2004). One of the most widely researched and accepted models of emotion regulation is Gross's Process Model of Emotion Regulation, which uses the Modal-Model of emotion generation as a framework to identify five points of potential emotion modulation within any given situation (Gross, 1998). For example, an individual might choose not to place themselves in a certain situation, in an attempt to regulate emotion. Alternatively, they could choose to alter, not attend, cognitively re-frame, or modulate their response to a certain situation, in an attempt to regulate their emotion (Gross, 2015).

Figure 2

The Process Model of Emotion Regulation.



Note. Obtained from Journal of Psychological Inquiry, "Emotion Regulation: Current Status and Future Prospects" by J.J. Gross. Copyright 2015 by Taylor & Taylor & Francis Group. Used with Permission.

The Extended Process Model (EPM) of emotion regulation was developed as an extension of Gross's Process Model of Emotion Regulation (Gross, 2015). The EPM theorizes that in addition to the primary system of emotion generation and modulation, there is a secondary valuation system which builds cognitively upon the first including: (1) emotion dysregulation identification, (2) selection of regulation strategy, and (3) implementation of emotion regulation strategy (Gross, 2015). At each point within the Process Model of emotion regulation, these secondary processes of identification, selection and implementation, are employed. Both the Process Model and the Extended Process Model tend to emphasize access to emotion regulation strategies, as well as the importance of goal-directed behaviour in modulating emotions, with the Extended Process Model also emphasizing the importance of the identification of emotions (Gross, 1998; Gross, 2015).

While the Process Model and Extended Process Model of emotion regulation are widely cited in the literature, alternative models of emotion regulation, such as the Experiential-Dynamic Emotion Regulation model (EDER), have also been developed. The EDER posits that it is not deficit in cognitive modulation of emotion that causes emotion dysregulation, but a tendency for individuals to avoid experiencing emotions by masking them with anxiety and defenses (Frederickson et al., 2018; Grecucci et al., 2020). The EDER model theorizes that emotions can be generated before any cognitive appraisal of situation occurs, and that emotions are not dysregulating in and of themselves, but help achieve regulation (Grecucci et al., 2020). Using the EDER model, treating emotion dysregulation involves helping facilitate affective experiences and clarity of emotions (Grecucci et al., 2020).

Gratz & Roemer (2004), integrated theories and empirical work of their time, to create an inclusive conceptualization of emotion regulation that includes: (1) awareness and understanding; (2) acceptance; (3) ability to control impulses;, (4) ability to use strategies to modulate emotions; and (5) to change behaviour according to a goal. Additionally, they posited that experiencing difficulty in any of these emotion regulation abilities, might indicate the presence of emotion dysregulation (Gratz & Roemer, 2004). For example, one could not be expected to regulate their emotions should they be unaware of them. The same is true of denying emotions, being impulsively emotionally expressive, lacking effective strategies, or the planning ability to change behaviour according to an emotion regulation goal. As such, deficits in any one emotion regulation subskill might lead to the same outcome of emotion dysregulation.

Emotion regulation has been shown to be amenable to intervention in various populations, such as with people diagnosed with anxiety (Mennin et al., 2018), as well as caregivers of those with cancer (O'Toole et al., 2019). Additionally, feasibility studies of emotion regulation intervention among individuals with chronic health conditions, such as HIV and cardiac rehab patients, have been promising (Parsons et al., 2017; Wierenga et al, 2021). For example, Wierenga and colleagues (2021) completed a feasibility study of an emotion regulation group therapy program for patients in cardiac rehabilitation with participant (n=14) responses indicating that the intervention was feasible, with several strengths. Despite there being limited research to date, the relevance of emotion-regulation focused interventions for those with MS is certainly pertinent given our understanding of emotion dysregulation in MS. In particular, a study completed by Philips and colleagues (2014) identified that patients with MS (n=31) experience more

difficulties in self-reported emotion regulation according to their endorsed responses on the Difficulties in Emotion Regulation Scale (DERS) than healthy controls, independent of executive dysfunction. A study completed by Carvalho and colleagues (2021), aimed at understanding stress among those with MS, identified that experiential avoidance (related to emotion regulation process), years of education, number of relapses, and fatigue increased participants (n=101) level of stress. Most promisingly, a randomized control trial (n=70) which allocated participants with MS into a treatment as usual (TAU) group and a group that was provided treatment according to the Unified Protocol for Treatment of Emotional Disorders, showed significant decrease in emotion dysregulation, in addition to depressive symptoms, anxiety, and affectivity (Nazari et al., 2020). Interestingly, according to a study completed by Sadeghi Bahmani and colleagues (2020) emotion regulation among those with MS was also found to be positively impacted by physical activity interventions.

While previous research indicates that emotion dysregulation is relevant and malleable to intervention among patients with MS (Carvalho et al., 2021; Nazari et al., 2020; Sadeghi Bahmani et al., 2020), there is a gap in the research in terms of whether the effective treatment of emotion dysregulation might lead to greater HRQOL. Health-related quality of life is conceptualized to be a part of overall quality of life, with HRQOL accounting for 69%-75% of the variance in overall quality of life (Palimaru & Hays, 2017). Some research has indicated a connection between emotion regulation, and overall quality of life. For example, a mediation analysis of 31 patients with MS, and 31 healthy controls which examined emotion regulation as measured by the Difficulties in Emotion Regulation Scale (DERS), and overall quality of life in patients found that depressive

symptoms mediated the relationship between emotion dysregulation and overall quality of life, while executive function did not (Phillips et al., 2014). The importance of emotion regulation on overall quality of life is further supported by a cross-sectional, self-report study that found that dispositional mindfulness (i.e., the ability to attend to one's present experiences) was positively associated with overall quality of life among patients with MS (n=95), with lower emotion dysregulation partially mediating this relationship (Schirda et al., 2015). Expanded work by Prakash et al. (2019) found that emotion dysregulation was associated with symptoms of depression and anxiety in a cross-sectional self-report study which compared an MS group (n=100) to a community control group (n=98), with higher rates of depressive symptoms, increased emotion dysregulation, and lower HRQOL found in the MS group.

While keeping in mind the Revised Wilson & Cleary model of HRQOL, it is conceptually possible that the individual characteristic of emotion regulation ability has a direct relationship with health-related quality of life among patients with MS, independent of disease-characteristics and environmental characteristics. Alternatively, the individual characteristic of emotion regulation ability could have a direct impact on disease-specific factors, leading to decreased HRQOL overall. There is a lack of research investigating the potential link between emotion dysregulation and health-related quality of life among patients with MS, underscoring the need for further exploration, especially given the malleability of emotion dysregulation. Further bolstering the importance of this avenue of research, are findings of several studies which have examined the relationship between emotion regulation abilities and HRQOL in other chronic conditions (Ferda & Gurel, 2020; Fino et al., 2021; Innamorati et al., 2016). For example, in a cross-sectional

study which examined 193 women living with endometriosis, it was found that physical pain and emotion regulation abilities were the main correlational predictive factors of mental health-related quality of life as measured by the SF-36 (Márki et al., 2017). In a study comparing adult outpatients with psoriasis with healthy controls, it was found that difficulties with emotion regulation among other variables, was associated with poor mental health related quality of life (MHRQOL) (Innamorati et al., 2016). A more recent study of 130 patients with mild psoriasis found that emotion regulation and social anxiety contributed to health-related quality of life (Fino et al., 2021). As MS is also a chronic condition, associated with particularly poor HRQOL, as well as emotion regulation difficulties, examining whether emotion regulation is associated with HRQOL might provide future direction for targeted intervention. Factors that have been identified as highly contributary to HRQOL in those with MS, include gender, age and social support (Biernacki et al., 2019; Casetta et al., 2009; Raymakers et al., 2017; Costa et al., 2012; Ponzia et al., 2020). While researchers have started to examine the contributing factors leading to poor health-related quality of life of those with MS (Cederberg et al., 2020; Biernacki et al., 2019), emotion regulation has not been the focus of examination to date.

2.4 The Current Study

The current study aimed to examine the self-reported emotion regulation abilities of patients with MS, and the relationship between emotion regulation, mental health-related quality of life, and physical health-related quality of life. As the prevalence of MS in Canada is among the highest reported in the world, with individuals typically first impacted within their young adult years, the individual and societal costs of MS disease are substantial. Despite the negative impact of MS on Canadians, the majority of research

on emotion regulation among those with MS has been completed outside of Canada. Additionally, to the best of our knowledge, there is no published research examining the relationship between emotion regulation and HRQOL among patients with MS. Therefore, the aim of this study is to build a knowledge base from which future clinical intervention and research can be well-planned. Specific aims include an examination of:

1. The sociodemographic and clinical characteristics of our Canadian sample with MS.
2. The relationship between difficulties in emotion regulation and HRQOL in patients with MS.
3. To what degree emotion regulation predicts HRQOL, over and above previously identified sociodemographic and clinical characteristics of importance (i.e., age, gender, social support).

Chapter 3: Methodology

3.1 Participants

Eligible participants were adult residents of Newfoundland and Labrador diagnosed with Multiple Sclerosis (MS). No other exclusionary criteria were applied in order to fully capture the range of experiences of those with MS. Collection of data took place from June 2015 – April 2018, with the lengthy collection time being due to initial low response and therefore slow recruitment.

An a priori power analysis was conducted using G*Power 3.1.9.7 (Faul et al., 2007) to determine (1) the minimum sample size required to test the relationship between difficulties in emotion regulation and HRQOL, as well as, (2) the minimum sample size required to identify to what degree emotion regulation predicts HRQOL over and above previously identified clinical characteristics of importance. Results indicated that the required sample size to achieve 80% power for detecting a large effect, at a significance criterion of $\alpha = .05$, was $N = 29$ for Pearson's correlation. A sample size of 84 participants would be required to detect a medium effect within the same statistical parameters. As such, the obtained sample size of 54 participants is adequate to detect a large, but not medium, or small effect within the correlational data.

In terms of determining a significant regression coefficient , results indicated the required sample size to achieve 80% power for detecting a large effect of one tested predictor from a total of four predictors, at a significance level of $\alpha = .05$, was $N= 25$. A sample size of 55 participants would be required to detect a medium effect within the same statistical parameters, just above our obtained sample size of 54 participants. For detecting a significant regression coefficient for our hierarchical regression with added

predictors, results indicated the required sample size to achieve 80% power for detecting a large effect of six tested predictors from a total of nine predictors, at a significance level of $\alpha = .05$, was N= 47. A sample size of 98 participants would be required to detect a medium effect size within the same statistical parameters. As such, the obtained sample size of 54 participants is adequate to detect a large, but not small or medium effect within this specific hierarchical model.

3.2 Procedure

Participants were recruited through two different pathways. The first pathway involved recruitment of participants (n=25) in partnership with Eastern Health's Neurology Clinic at the Health Sciences Center in St. John's, NL. As standard procedure at the Neurology Clinic, patients are asked at their intake appointment whether they consent to being contacted regarding participation in future research projects. Those patients who had indicated they might be interested in participating in ethics-approved research were contacted by a graduate student who explained the project and addressed any questions or concerns. A mail-out package with consent forms, sociodemographic questionnaire, and study measures were sent to interested participants with a pre-paid, pre-addressed envelope for return, see Appendix D for consent forms. The recruitment of participants through the Neurology Clinic pathway was low, likely due to another larger study drawing from the same populations.

In order to increase the sample size, additional participants were recruited through a second pathway using social media, posters, and brochures (n=29), see Appendix E and Appendix F. Moreover, a presentation was provided by Dr. Kellie Hadden to members of the Avalon MS Association to further explain the research and recruit participants. All

recruitment materials included a link to an online Qualtrics survey which replicated the questionnaires that were previously completed by the first pathway of recruitment through the Neurology clinic. Additionally, contact information was provided on recruitment materials so that paper versions of the survey could be requested, if preferred to online survey. The contact information on the recruitment materials also allowed participants to reach out with any questions or concerns about study participation. In all, 25 participants completed mail-out paper questionnaires, while 29 participants completed the online questionnaires.

Participants were not required to answer all sociodemographic questions in order to complete the study. They could skip any question they felt uncomfortable answering. For additional security, participants remained anonymous, with no easily identifiable information collected (e.g., name, date of birth). In order to track participants, a participant ID number was assigned following the completion of the survey. The anonymous data was exported from Qualtrics to SPSS for statistical analysis, or entered manually from paper-surveys.

3.3 Measures

Sociodemographic Form. A broad range of sociodemographic information was asked including general information (i.e., gender, age, education), and clinical information (i.e., type of MS, duration of illness, symptoms) (see Appendix A for sociodemographic questionnaire). It should be noted that the socio-demographics and below measures were collected as a part of a battery of questionnaires within the context of a larger project.

12-Item Short-Form Health Survey. The SF-12 Health Survey (SF-12 HS) is based on the Short Form 36-item Health Survey (SF-36 HS) that has been widely used as an indication of the health-related quality of life for patients with chronic illnesses (Hagell & Westergren, 2011), see Appendix C. The SF-12 HS yields two summary measures: The Physical Component Summary and the Mental Component Summary. The SF-12 HS has been shown to closely relate to the Medical Outcome Study (MOS) SF-36 with high reliability of 0.91 and 0.92 for the Physical Component Summary and the Mental Component Summary respectively (Grassi & Nucera, 2010). Test-retest scores for SF-12 HS were 0.89 and 0.76 (Ware et al., 1996). The scores are based on norms with higher scores indicating better health related quality of life.

Difficulties in Emotion Regulation Scale. The Difficulties in Emotion Regulation Scale (DERS) is a 36-item self-report questionnaire that assesses multiple aspects of emotion regulation, see Appendix B. The DERS yields six subscale scores and a total score, ranging from 36-180. The subscales are: (1) acceptance of emotion, (2) ability to engage in the goal-directed behaviour when distressed, (3) impulse control, (4) awareness of emotions, (5) access to strategies for regulation, and (6) clarity of emotions. The participant rates the DERS items (i.e., "When I'm upset, I become embarrassed for feeling that way") on a 5-point scale from "almost never" to "almost always". The DERS has been shown to have good psychometric properties across age and ethnicity (Ritschel et al., 2015). The initial validation study for the DERS demonstrated a high internal consistency ($\alpha = 0.93$), good test-retest reliability of total score ($\rho_I = 0.88$), and adequate test-retest reliability of subscale scores ($\rho_I = 0.69$ for nonacceptance, $\rho_I = 0.69$ for goals,

ρ_I =0.57 for impulse, ρ_I = 0.68 for awareness, ρ_I = 0.89 for strategies, ρ_I = 0.80 for clarity) (Gratz & Roemer, 2004).

3.4 Statistical Analysis

The IBM Statistical Package for the Social Sciences, version 23 (SPSS V.23), R 3.6.1 (MICE package), and G*Power 3.1.9.7 were used for data analysis.

Data Screening. Participant data was screened for eligibility criteria (i.e., adults living in Newfoundland & Labrador), and only participants who progressed beyond the sociodemographic questions were included. Out of all individuals who had started the survey (n=69), 54 participants met eligibility criteria and progressed beyond the sociodemographic questions. Data from 54 participants were then screened for potential univariate and multivariate outliers. No univariate outliers that exceeded a z-score of 3.29 were identified for variables of interest (Tabachnik & Fidel, 2018). Multivariate outliers were assessed using Mahalanobis distances with no identified outliers exceeding a χ^2 critical value associated with a $p < .001$ (Tabachnik & Fidel, 2018). Variables of interest were screened for skewness and kurtosis, with all variables analyzed to be within acceptable range as seen in Table 1.

Table 1

Skewness and Kurtosis Values of Study Variables

	Skewness		Kurtosis	
	Statistic	S.E.	Statistic	S.E.
Emotion Regulation Total	.622	.330	.081	.650
Clarity	1.004	.330	.658	.650
Goals	.179	.327	-.207	.644

Awareness	.533	.327	-.421	.644
Non-Acceptance	.726	.327	-.433	.644
Impulses	1.423	.327	1.899	.644
Strategies	1.082	.327	1.043	.644
Mental Health Related Quality of Life	.091	.481	-1.058	.935
Physical Health Related Quality of Life	-.143	.481	.184	.935

Due to random clerical error, the initial batch of paper questionnaires were missing questions 6, 7, 8, of the SF-12 causing a large gap in data of approximately 57.4% for these three questions, as well as subsequently overall physical and mental health related quality of life. All other scales, subscales, and sociodemographic variables of interest had <5% of data missing, with the exception of social support which had 11.1% of data missing, as seen in Table 2. Little's MCAR Test was completed to test the hypothesis that there were no patterns within the missing data, X^2 (383, 53) = 383.640, p = .481. Fortunately, missing data was able to be handled using multiple imputation method of 10 iterations, a particularly strong method for ensuring that data maintains a high level of integrity (Little & Rubin, 2002; Dong & Peng, 2013).

Table 2

Percentage of Missing Data of Study Variables

Variable	Missing data (%)
Age	0.0
Sex	3.7
Social Support	11.1
Difficulties in Emotion Regulation (DERS)	3.7

Clarity	3.7
Goals	1.9
Impulsivity	1.9
Strategies	1.9
Awareness	1.9
Non-Acceptance	1.9
Physical Health Related Quality of Life	57.4
Mental Health Related Quality of Life	57.4

In order to better understand the reliability of the DERS and SF-12 HS on the study sample, Cronbach's alpha was calculated for all subscales. As can be seen from Table 3 below, the DERS yielded particularly good reliability, ranging from $\alpha = .939$ for overall emotion regulation, to $\alpha = .793$ for the subscale of awareness. In terms of both mental and physical health related quality of life, the current sample's endorsed responses resulted in a lower reliability of $\alpha = .465$ for mental health related quality of life, an $\alpha = .564$ for physical health related quality of life, as seen in Table 3.

Table 3

Cronbach's Alphas of Subscales of Study Variables

	Items	Cronbach's α
Emotion Regulation Total	36	.939
Clarity	5	.820
Goals	5	.816
Awareness	6	.793
Non-Acceptance	6	.924

Impulses	6	.873
Strategies	8	.824
Mental Health Related Quality of Life	12	.465
Physical Health Related Quality of Life	12	.564

Data Analysis. First, a frequency analysis was conducted to better understand the sociodemographic variables associated with the sample. In order to manage missing data, a multiple imputation database of 10 iterations was generated using data at the item-level. Secondly, correlational analysis was completed to assess the relationship between demographic variables and study variables, including emotion regulation as measured by the DERS and HRQOL as measured by the SF-12 HS. Finally, the predictive role of emotion regulation (total DERS score, and DERS subscale scores) on physical and HRQOL were analyzed using separate hierarchical multiple regressions.

A sensitivity analysis was conducted using the software package, G*Power 3.1.9.7 (Faul et al., 2007; Faul et al., 2009). Effect sizes used within regression analysis as recommended by Cohen (1988) include, small ($f^2 = .02$), medium ($f^2 = .15$), and large ($f^2 = .35$). The alpha level used for this analysis was $p < .05$, with a power of 80%. Given an obtained sample size of 54 participants used in testing one predictor variable within a total four-predictor variable equation (i.e., predictors of age, gender, social support, and DERS total), the effect was determined to be detectable when of medium or larger size ($f^2 = .15$) for the first two completed hierarchical regressions. Given the same statistical parameters (i.e., $p < 0.05$, power of 80%) when testing six predictor variables within a

total nine-predictor variable equation, the effect was determined to be detectable only when of large size ($f^2 = .29$).

Chapter 4: Results

4.1 Participant Sociodemographic Characteristics

The final sample included 54 adults with Multiple Sclerosis (14 males, 38 females, 2 unreported; M_{Age} = 45.61 yrs, SD = 12.24) from across Newfoundland and Labrador, Canada (see Table 4 for sociodemographic characteristics of participants). On average, individuals had been living with MS for almost a decade ($M_{YearsMS}$ = 9.61 yrs, SD = 8.61) after being diagnosed in early to middle adult years (M_{AgeDx} = 36.37 yrs, SD = 8.84). In terms of mode of administration, 53.70% of individuals completed online questionnaires while 46.30% completed paper and pencil questionnaires.

Household income varied across participants as follows: <$10,000 (12.96%), $10,000 - $19,999 (7.41%), $20,000 - $29,999 (5.56%), $30,000 - $39,999 (7.41%), $40,000 - $49,999 (0.00%), $50,000 - $74,999 (14.81%), $75,000 - $99,999 (16.67%), >$100,000 (24.04%), and unreported (11.11%). Education also varied across participants with the majority of individuals indicating some form of post-secondary completion (81.48%; 3.70% unreported). Half of participants (50.00%) identified that they had experienced an employment change due to their MS diagnosis, with the largest percentage of participants indicating that they were currently employed (38.89%). An additional 27.78% of participants indicated that they were retired, 14.81% identified their employment as “Other”, 12.96% reported currently being unemployed and 5.56% indicated that they were a student.

While 62.96% of individuals indicated being married and 3.70% indicated living with a partner, 18.52% of individuals reported being single with a further 11.11% divorced/separated. Our participants appeared to be relatively well supported with

66.67% feeling as though they had enough social support. Half of participants (50%) identified that they had four or more people for support, 18.52% specified three people for support, 5.56% specified two people for support, 7.41% specified one person for support, 7.41% indicated no supportive people.

Individuals primarily reported a diagnosis of Relapse Remitting Multiple Sclerosis (70.37%), followed by Primary Progressive Multiple Sclerosis (14.81%) and Progressive Relapsing Multiple Sclerosis (5.56%), with a remainder of participants not reporting their specific subtype (9.26%). The majority of participants indicated that their MS had had a negative impact on their physical functioning (77.78%; 7.41% unreported). Symptoms of concern most prevalent in our sample were fatigue (57.41%), physical impairment (53.70%), balance and dizziness (53.70%), cognitive decline (42.59%), and sensory impairment (48.15%).

As a broad socio-demographic questionnaire was provided including additional questions surrounding our participants, some additional variables of potential interest are also reviewed below. Fifty percent of participants indicated that they drank alcohol (14.81% unreported) while 22.22% of participants indicated that they used non-prescription drugs (59.26% unreported). Surprisingly, 24.07% of participants indicated that they had previously had a head injury.

Table 4

Sociodemographic Characteristics of Participants

Characteristic		
	M	*SD*
Age	45.61	12.24
Age Diagnosed with Multiple Sclerosis	36.37	8.84

Years Living with Multiple Sclerosis	9.61	8.61
	n	*%*
Gender		
Male	14	25.93
Female	38	70.37
Unreported	2	3.70
Type of MS		
Primary Progressive	8	14.81
Progressive Relapsing	3	5.56
Relapse-Remitting	38	70.37
Unreported	5	9.26
Income		
Under $10,000	7	12.96
$10,000 - $19,999	4	7.41
$20,000 - $29,999	3	5.56
$30,000 - $39,999	4	7.41
$40,000 - $49,999	0	0.00
$50,000 - $74,999	8	14.81
$75,000 - $99,999	9	16.67
Over $100,000	13	24.04
Unreported	6	11.11
Education		
Elementary/Junior High School	1	1.85
Some High School	1	1.85
High School	6	11.11
Technical School (2 year)	9	16.67
College	13	24.07
University Bachelor's Degree	15	27.78
Master's Degree	7	12.96
Professional Degree	0	0.00
Unreported	2	3.70
Marital Status		
Divorced/Separated	6	11.11
Living with Partner	2	3.70
Married	34	62.96
Single	10	18.52
Unreported	2	3.70
Children in Household		
None	33	61.11
One	11	20.37
Two	5	9.26
Three	0	0.00

Four or more	1	1.85
Unreported	4	7.41
Employment		
Unemployed	7	12.96
Retired	15	27.78
Employed	21	38.89
Student	3	5.56
Other	8	14.81
Unreported	0	0.00
Employment Status Change		
Yes	27	50.00
No	20	37.04
Unreported	7	12.96
Enough Support		
Yes	36	66.67
No	12	22.22
Unreported	6	11.11
Number of People for Support		
None	4	7.41
One person	4	7.41
Two people	3	5.56
Three people	10	18.52
Four or more	27	50.00
Unreported	6	11.11
Pain in Daily Life		
0 – No Pain	8	14.81
1	10	18.52
2	10	18.52
3	2	3.70
4	2	3.70
5	6	11.11
6	3	5.56
7	6	11.11
8	0	0.00
9	0	0.00
10 – Worst Pain Possible	0	0.00
Unreported	7	12.96
Impact on Physical Function		
Yes	42	77.78
No	8	14.81
Unreported	4	7.41

Symptoms of Concern		
Physical Impairment	29	53.70
Cognitive Decline	23	42.59
Depression	11	20.37
Anxiety	13	24.07
Pain	15	27.78
Balance and Dizziness	29	53.70
Bladder Dysfunction	14	25.93
Fatigue	31	57.41
Sensory Impairment	26	48.15
Tremors	9	16.67
Burning Sensation	9	16.67
Other	6	11.11
None	1	1.85
Drug Use		
Yes	12	22.22
No	20	37.04
Unreported	32	59.26
Alcohol Use		
Yes	27	50.00
No	19	35.19
Unreported	8	14.81
Head Injury		
Yes	13	24.07
No	34	62.96
Unreported	7	12.96

Note. N=54.

4.2 Descriptive Statistics for Study Variables

In order to better understand our sample, pooled means and standard deviations of all study variables (i.e., total emotion regulation and associated subscales, mental and physical health related quality of life) from the generated multiple imputation database, are presented in Table 5.

Table 5

Pooled Means and Standard Deviations of Study Variables

	M_{pooled}	SD
Difficulties in Emotion Regulation (DERS)	81.42	23.35
Clarity	10.75	3.88
Goals	13.98	4.58
Impulsivity	11.22	5.06
Strategies	16.35	5.90
Awareness	15.27	5.09
Non-Acceptance	13.86	6.51
Physical Health Related Quality of Life	35.71	9.43
Mental Health Related Quality of Life	44.16	9.30

4.3 Correlational Analysis

A Pearson correlation was conducted on the multiple imputation database to better understand the relationship between study variables. As can be seen in Table 6, Gender was not correlated with study variables of interest, while the variable of Age, $r(54) = -.31$, $p < 0.05$, was negatively correlated with total DERS score, indicating that a higher age was associated with decreased emotion dysregulation. Results indicated that Age was also significantly negatively correlated with the DERS subscales of Clarity, $r(54) = -.30$, $p < 0.05$, and Goals, $r(54) = -.32$, $p < 0.05$, indicating that as our sample aged, emotion regulation skills related to constructs of clarity and goal-directed modulation of emotion improved. Neither Age nor Gender were correlated with mental health related quality of life (MHRQOL) or physical health related quality of life (PHRQOL). Social support, as

measured by the number of individuals a participant was able to 'count on' for support, was significantly negatively correlated with PHRQOL, $r(54) = .30$, $p < 0.05$ and the DERS subscale of Impulses, $r(54) = -.31$, $p < 0.05$. Social support was not correlated with MHRQOL. Results also indicated that total DERS score was significantly negatively correlated with MHRQOL, $r(54) = -.47$, $p < 0.01$), showing that as emotion dysregulation increased, MHRQOL decreased. In terms of the relationship of DERS subscales with MHRQOL, results demonstrated that Clarity, $r(54) = -.36$, $p < 0.01$, Goals, $r(54) = -.53$, $p < 0.01$, Impulses, $r(54) = -.44$, $p < 0.01$, Strategies, $r(54) = -.44$, $p < 0.01$, and Non-acceptance, $r(54) = -.29$, $p < 0.05$ were significantly negatively correlated with MHRQOL. Interestingly, neither total DERS score or its associated subscales were correlated with Physical Health Related Quality of Life (PHRQOL).

Table 6

Pooled Correlations for Study Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. DERS – Total Score	1											
2. DERS – Clarity	.783**	1										
3. DERS – Goals	.780**	.661**	1									
4. DERS – Impulses	.852**	.709**	.659**	1								
5. DERS – Awareness	.501**	.345**	.183	.248	1							
6. DERS – Strategies	.833**	.545**	.587**	.674**	.324*	1						
7. DERS – Non-Acceptance	.764**	.431**	.513**	.588**	.194	.567**	1					
8. MHRQOL	-.466**	-.356**	-.531**	-.438**	-.080	-.436**	-.287*	1				
9. PHRQOL	-.164	-.117	-.112	-.225	-.049	-.144	-0.96	-.276	1			
10. Age	-.305*	-.301*	-.323*	-.256	-.165	-.204	-.176	.171	-.254	1		
11. Gender	-.002	.022	.241	.010	-.242	-.044	.031	.109	-.137	-.086	1	
12. Social Support	-.267	-.173	-.090	-.312*	-.204	-.265	-.151	.094	.296*	-.045	.275	1

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

4.4 Hierarchical Regression Analyses Predicting HRQOL

In order to determine whether emotion regulation predicts MHRQOL, over and above previously identified sociodemographic and clinical characteristics of importance (i.e., age, gender (0=male, 1=female), social support), a hierarchical multiple regression was performed using data from the multiple imputation database.

As can be seen in Table 7, a significant regression equation was found with emotion regulation predicting MHRQOL, after controlling for age, gender, and social support, $F(4, 50) = 11.253$, $p < .01$, adj. $R^2 = .1761$. More specifically, age and gender were entered in the first step and results indicated that these variables accounted for <1% of the variance in MHRQOL, $F(2, 52) = 1.175$, $p = .309$. Social support was entered in the second step, with a percentage change in variance of <1% in MHRQOL, $F(3, 51) = 0.207$, $p = .649$. Finally, when emotion regulation was added into the third step, it was found to account for 17.96% of the variance in MHRQOL, $F(4,50) = 11.253$, $p < .01$, $f^2 = 0.22$. It was determined that with the current study's sample size, four predictors, effect size, and the calculated ΔR^2, the observed power for this regression was 0.75.

Table 7

Summary of Hierarchical Regression Analysis for Pooled Variables Predicting Mental Health Related Quality of Life

Model	Predictor	*B*	*SE*	*β*	*t*	*p*	*Adj. R^2*	*p*	*F change*	*Sig. F Change*
1							.0095	.309	1.175	0.30877
	Age	.138	.106	.181	1.304	.192				
	Gender	2.596	3.060	.124	.848	.397				
2							-.0035	.462	0.207	0.64923
	Age	.138	.106	.182	1.301	.193				
	Gender	2.196	3.218	.105	.683	.495				
	Social Support	.531	1.092	.073	.486	.627				
3							.1761	.00666**	11.253	.0008**
	Age	.025	.103	.033	.246	.806				
	Gender	2.722	2.983	.130	.913	.362				
	Social Support	-.498	1.066	-.068	-.467	.641				
	DERS Total	-.189	.056	-.474	-3.385	.001**				

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

In order to better understand which subscales of the DERS were contributing the most variance within the statistically significant regression model, an additional hierarchal regression was performed using data from the multiple imputation database. Analysis of collinearity indicated that the variance inflation factor (VIF) for all variables of interest were below the threshold for multicollinearity (<10; Kim, 2019). The subscales of the DERS were found to better predict MHRQOL, with the subscale of 'Goals' contributing to the most variance after controlling for gender, age, and social support $F(9, 45) = 3.629$, $p = .005$. As can be seen in Table 8, gender was entered into the first step accounting for <1% of the variance in MHRQOL, $F(2, 52) = 1.175$, $p = .309$. Social support was entered in step two, with the percentage change in variance of <1% in MHRQOL, $F(3, 51) = 0.207$, $p = .649$ When the subscales of the DERS were added into the third step, they account for 25.74% of the variance in MHRQOL, $F(9, 45) = 3.629$, $p < .005$, adj. $R^2 = .2574$, $f^2 = 0.22$. It was determined that with the current study's sample size, nine predictors, effect size, and the calculated ΔR^2, the observed power for this regression was 0.80.

Table 8

Summary of Hierarchical Regression Analysis for Pooled Variables and DERS Subscales Predicting MHRQOL

Model	*Predictor*	*B*	*SE*	*β*	*t*	*p*	*Adj. R^2*	*p*	*F change*	*Sig. F change*
1							.0095	.309	1.175	0.30877
	Age	.138	.106	.181	1.304	.192				
	Gender	2.596	3.060	.124	.848	.397				
2							-.0035	.462	.207	0.64923
	Age	.138	.106	.182	1.301	.193				
	Gender	2.196	3.218	.105	.683	.495				
	Social Support	.531	1.092	.073	.486	.627				
3							.2574	.00351**	3.629	.00141**
	Age	.007	.103	.033	.246	.806				
	Gender	5.754	2.983	.130	.913	.362				
	Social Support	-.479	1.066	-.068	-.467	.641				
	DERS Goals	-1.102	.394	-.543	-2.799	.005**				
	DERS Impulsive	-.252	.393	-.137	-.641	.522				
	DERS Strategies	-.264	.285	-.167	-.925	.355				
	DERS Clarity	.243	.462	.102	.526	.599				
	DERS Awareness	.201	.253	.110	.793	.428				
	DERS Non-Accept	.123	.227	.086	.543	.587				

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

To gain a better understanding of whether emotion regulation predicts physical health related quality of life, over and above age, gender and social support, a hierarchical regression was performed using the multiple imputation database. As can be seen from Table 9, individual factors of gender and age were found to account for 5.67% of the variance in PHRQOL, $F(2, 52) = 2.24$, $p = .107$. Social support was entered into the second step, accounting for the majority of variance in the equation, an additional 10.46% of unique variance, $F(3, 51) = 6.831$, $p < .05$. Finally, emotion regulation accounted for an additional 1.73% of unique variance in PHRQOL, $F(4, 50) = 1.605$, $p = .205$, and was therefore not significant. It was determined that with the current study's sample size, four predictors, effect size, and the calculated ΔR^2, the observed power for this regression was 0.082, indicating there was a low probability of detecting an effect.

Table 9

Summary of Hierarchical Regression Analysis for Pooled Variables Predicting Physical Health Related Quality of Life

Model	*Predictor*	*B*	*SE*	*β*	*t*	*p*	*Adj. R^2*	*p*	*F change*	*Sig. F change*
1							.0567	.107	2.24	.10715
	Age	-.207	.106	-.2701	-1.955	.051				
	Gender	-3.386	2.976	-.1601	-1.138	.255				
2							.1613	.00804**	6.831	.00902**
	Age	-.201	.101	-.2601	-1.994	.046				
	Gender	-5.435	2.909	-.2571	-1.868	.062				
	Social Support	2.634	1.006	.3548	2.618	.009				
3							.1736	.00819**	1.605	0.20534
	Age	-.244	.106	-.3166	-2.312	.021*				
	Gender	-5.232	2.874	-.2474	-1.821	.069				
	Social Support	2.242	1.046	.3018	2.144	.032*				
	DERS Total	-.072	.057	-.1793	-1.274	.203				

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

Chapter 5: Discussion

5.1 Impact of Emotion Regulation on Health-Related Quality of Life

The current study examined sociodemographic characteristics of Canadians with Multiple Sclerosis (MS) and the impact of emotion regulation (ER) on their mental and physical health related quality of life (HRQOL). The objectives of the current study were to better understand the sociodemographic and clinical characteristics of our Canadian sample with MS, as well as the relationship between difficulties in emotion regulation and HRQOL.

The main finding of the current study was that emotion regulation significantly predicted MHRQOL, over and above gender, age, and social support, in a cross-sectional sample of adults with MS. This finding suggests that emotion regulation is a construct that is of importance for the understanding and management of MHRQOL among patients with MS. In examining previous literature, there is some understanding of the potential role of emotion regulation in people with Multiple Sclerosis (MS). For example, emotion dysregulation occurred in 6.5% of evaluated MS patients (n=651) with 66.6% presenting with comorbid psychopathology (e.g., mood disorders, psychosis, personality disorder) as assessed within a psychiatric interview (Harel et al., 2007). Phillips and colleagues (2014) identified that patients with MS (n=31) experience more difficulties in emotion regulation than healthy controls. Additionally, they found that emotion regulation difficulties predicted worse psychological quality of life in people with MS, independent of executive dysfunction. Of further note, several studies have previously identified predictors of HRQOL and broader QOL among those with MS, such as age, gender, depressive symptoms, anxiety, fatigue, level of disability, and duration of illness (Berrigan et al.,

2016; Wu et al., 2007; Casetta et al., 2009; Costa et al., 2012; Kever et al., 2021); however, there is a gap in the research in terms of identifying transdiagnostic factors that are amenable to intervention among those with MS, of which emotion regulation is a key construct underlying most psychological disorders. Perhaps more importantly, there is limited knowledge of whether emotion regulation and HRQOL are related, such that transdiagnostic treatment is clinically meaningful for those with MS. As such, current research findings provide insight into the importance of the relationship between ER and HRQOL for those with MS, over and above previously identified factors (e.g., age, gender, social support).

Several studies have previously identified the importance of emotion regulation in HRQOL among individuals with other chronic conditions (Fino et al., 2021, Márki et al., 2017). In particular, Fino and colleagues (2021) examined adults with mild-to-severe psoriasis (N=130) and found that emotion dysregulation and social anxiety contributed to HRQOL. The authors suggested that given the high psychosocial burden associated with psoriasis, independent of illness severity, therapeutic approaches that target emotion regulation skills might be useful in improving HRQOL and clinical outcomes among those with psoriasis through reducing exacerbating stress reactions (Fino et al., 2021; Fordham et al., 2015). Similarly, a cross-sectional study, which examined pain and psychological variables of 193 women with endometriosis, identified that emotion dysregulation and physical pain symptoms negatively impacted HRQOL through the mechanism of psychological stress (Márki et al., 2017).

Little research has been done in identifying how HRQOL might be impacted by associated symptoms of emotion dysregulation among individuals who experience neuro-

degenerative diseases; however, there have been some studies examining the role of emotion regulation in neuro-degenerative diseases (Löffler et al., 2016). For example, an examination of 13 individuals with pre-manifest Huntington's Disease (HD) compared to a matched control group found potential impairment of emotional awareness which was thought to present as a precursor to more significant emotion regulation difficulties once the disease clinically manifests (Zarotti et al., 2019). In another study, Ille and colleagues (2015) described people with Parkinson's Disease (PD) as reporting more difficulties with regulating feelings of anger and disgust, and recognizing emotions compared to healthy controls. In essence, despite emotion regulation being identified as a construct of interest within the neuro-degenerative disorder research, express links between emotion dysregulation HRQOL have yet to be examined thoroughly. The current study contributes to this literature by examining the impact of emotion dysregulation on the HRQOL of those with Multiple Sclerosis (MS).

Additionally, the current study has identified that the emotional regulation subskill of 'goals' (i.e., being able to still perform goal directed behaviour even when emotionally dysregulated), is the driving factor behind the relationship between HRQOL and emotion dysregulation. Contextually, this might mean that interventions that focus on behavioural activation or accommodation of emotion dysregulation in completing tasks might be the best avenue to further research. The importance of emotion in goal-directed behaviours has been identified as important with emotion found to trigger cognitive control in completion of tasks (Zinchenko et al., 2015; Bagozzi & Pieters, 1998). However, it appears within this research that being able to perform goal-oriented behaviour within the context of emotion dysregulation has a positive impact on MHRQOL. This might align

with Ochsner and Gross's conceptualization of emotion, in which bottom-up affective responses can be mediated by top-down cognitive re-appraisals of affective situations, likely allowing for a greater capacity of coping and higher capacity for goal-directed behaviours (2007).

The relationship between certain sociodemographic factors and emotion regulation within the current study was also noteworthy. For example, a negative association was observed between age and emotion regulation total scores, with younger participants struggling more with emotion regulation compared to older participants. Further evaluation of the subscales of the Difficulties in Emotion Regulation Scale (DERS) (i.e., clarity, goals, awareness, impulsivity, strategies, non-acceptance) and sociodemographic variables revealed two significant emotion regulation subscales (goals and clarity) were positively correlated with age. Specifically, older participants reported increased ability to modulate their emotions according to their goals, and more clarity in their understanding of their emotions. This positive correlation between age and emotion regulation is unsurprising given that aging has been found to be positively correlated with emotion regulation skills within the general population, particularly on subscales of goals and impulsivity (Orgeta, 2009). An additional correlation that was identified in the current study, was a negative correlation between emotion dysregulation and MHRQOL. As people reported increased total emotion dysregulation, including all subscales with the exception of the awareness subscale, MHRQOL decreased. While there is evidence of a significant relationship between emotion regulation and mental health within the literature, with most psychological disorders having emotion dysregulation symptoms, the vast majority of research focuses on mental health conditions as opposed to neuro-

degenerative disease (Márki et al., 2017, Berking & Wupperman, 2012). The current results indicate that emotion regulation continues to be significantly correlated to MHRQOL even when it potentially occurs as the result of acquired brain injury associated with MS.

Previous research has pointed to potential overlap between PHRQOL and emotion dysregulation (Kovac et al., 2018). For example, Trindade et al. (2018) found that certain maladaptive emotion regulation processes negatively impacted baseline levels of psychological and physical health in patients with Inflammatory Bowel Disease (IBD). Additionally, a narrative review found that emotion regulation influences physical health, in examining potential biological pathways of cardio-metabolic risk (Trudel-Fitzgerald et al., 2017). Despite these previous findings of the impact between emotion regulation and PHRQOL in certain populations, the current study did not confirm a relationship between emotion regulation and PHRQOL among patients with MS. One potential possibility for the lack of relationship between PHRQOL and emotion regulation in the current study might be that the average duration of illness of the sample was approximately 6 years less than previously researched studies using Canadian samples (Gilmour et al., 2018). However, similar to this study, Faraclas et al. (2022) found that mental, emotion, and social health influenced overall HRQOL more than physical health in their sample of people with MS. Additionally, they noted that earlier on in illness as well as with younger participants, mental health was found to be more negatively impactful on HRQOL than physical health (Faracles et al., 2022). Therefore, the younger age of the study sample might have contributed to the lack of findings between PHRQOL and emotion regulation.

5.2 Consideration of Sociodemographic Characteristics

Participants in the current study consisted of a community sample of patients with MS. All participants were living in Canada, specifically in the province of Newfoundland and Labrador. There were more women than men in the current study (sex ratio of 2.7: 1), which aligns well with previous epidemiological findings in Newfoundland & Labrador (sex ratio of 2.7:1) as well as findings from Statistics Canada on 2010/2011 data of Canadians with MS (sex ratio of 2.6:1) (Sloka et al., 2005; Gilmour et al., 2018). The average age of our sample with MS was approximately 45 years, while the average age they were diagnosed with MS was 36 years, meaning that on average our sample had been living with MS for approximately 9 years. According to Gilmour and colleagues (2018), the average age of MS diagnosis in Canada is 37 years old, which is similar to the current study sample (M_{AgeDx} = 36); however, they noted their average duration of illness was longer than the current study by approximately six years at the time of their data collection. Given the current sample was recruited from the community, it likely inadvertently excluded those from long-term care facilities or with more progressed symptoms, decreasing duration of illness, as well as the severity of illness, when compared to national Canadian data.

The majority of the current sample reported having a diagnosis of Relapsing-Remitting MS (RRMS), which is to be expected given the high rate of RRMS in previous Canadian research. In particular, Widdifield and colleagues (2015) reported that approximately two thirds of their cross-sectional sample (n= 73,003) in Ontario, Canada were diagnosed with RRMS. Menon and colleagues (2017), identified that 74.2% of patients in a sample of 235 with aggressive MS who lived in British Columbia had been

diagnosed with RRMS. Additionally, in an examination of the incidence and prevalence of MS in Newfoundland & Labrador, Sloka and colleagues (2005) also found two thirds of their sample as having RRMS. Therefore, the rate of RRMS in this current study is consistent with other Canadian studies (Widdifield et al, 2015; Menon et al., 2017). In terms of Primary Progressive Multiple Sclerosis (PPMS) & Progressive Relapsing Multiple Sclerosis (PRMS) subtypes, a small proportion of the current sample self-identified as having PPMS (14%), and an even smaller percentage identified having as having PRMS (5%). Sloka and colleagues identified that 13% incidence rate of PPMS in Newfoundland and Labrador in 2005, indicating that the rate of PPMS in the current study is consistent with other Canadian studies. Most interestingly, no participants in the current study identified having SPMS, despite an incidence rate of 19% identified previously in NL (Sloka et al., 2005). One potential explanation for the lack of reporting of SPMS is the overlap in features and disease mechanism between RRMS and SPMS with some emerging research indicating that RRMS and SPMS are part of the same subtype, with indistinct clinical markers for their distinction (Cree et al., 2021). Given the lack of clear boundary between these two subtypes of MS, it is possible that clear clinical communication to the patient surrounding when RRMS has reached threshold of SPMS might be less likely in favour of using SPMS as a working diagnosis. Additionally, given the self-report nature of this study, and that subtype can only be confirmed by an MS neurologist, some participants may not know their subtype or may not have been officially diagnosed with the secondary label of SPMS following initial diagnosis.

Neither age nor gender were correlated with MHRQOL or PHRQOL, which is interesting given that ageing would ostensibly lead to PHRQOL decline, however, this

was not detectable in the current study possibly due to small sample size and low statistical power compared to previous research (Christiansen et al., 2019). Consistent with research indicating social support is an important predictor in HRQOL in those with MS, social support was positively correlated with PHRQOL (Costa et al, 2012). Interestingly, MHRQOL was not positively correlated with social support as one would expect given previous findings (Kever et al., 2021). This is possibly due to how the questions were asked on the sociodemographic questionnaire, which included a singular question, as opposed to a multi-faceted standardized questionnaire of social support. Alternatively, the lack of correlation between social support and MHRQOL in the current study could mean that poor MHRQOL is an artifact of individual characteristics (e.g., neurocognitive functioning) as opposed to environmental characteristics (e.g., support systems).

Within previous research, several individual sociodemographic characteristics such as female sex, and increased age have been found to be negatively associated with HRQOL among people with MS (Biernacki et al., 2019; Stern et al., 2020). Additionally, disease-specific factors (e.g., symptoms, level of disability, treatments) have also been found to be instrumental in an individual's perception of their own health and well-being (Bužgová et al., 2020; Jongen, 2017). However, while the identification of static individual characteristics can help triage the provision of services to those who might be at highest risk for poor HRQOL, it does not provide a pathway to direct intervention. Some studies have identified depressive symptoms and fatigue as contributors to poor mental health among people with MS, with one study of 322 participants with RRMS identifying that psychopathological difficulties had a negative impact on HRQOL, over

and above physical impairment (Biernacki et al., 2019). These constructs are promising, as they allow for potential avenues of psychological and psychiatric treatment intervention related to managing symptoms of chronic fatigue and depressive symptoms. Understanding how HRQOL might be impacted by more dynamic, malleable constructs, such as emotion regulation abilities, is pertinent in ensuring those with MS have adequate HRQOL. As such, identifying the importance of the transdiagnostic construct of emotion regulation in people with MS, might allow for increased research and clinically meaningful intervention.

5.3 Strengths & Limitations

There are several study strengths which should be highlighted, including ecologically valid sample, and strong measure psychometrics. In particular, participants were recruited from multiple avenues (i.e., neurology clinic, online recruitment) with limited exclusion criteria which led to an ecologically valid sample that included a diverse number of presentations of MS. Indeed, if one examines the socio-demographics of the current sample, it would be found to be representative of the MS population within Canada, and Newfoundland and Labrador. However conversely, the sample was heterogenous, making it more difficult to detect effects within a small sample. That being said, given the high level of heterogeneity in MS with emotion dysregulation presenting as a symptom for some and not others, the examination of an ecologically representative sample as an initial investigation of potential factors for intervention is certainly desirable.

A further strength of this study is the use of validated psychometric measures. Utilization of well-researched measures of health-related quality of life and emotion

regulation allows for both comparison to previous research, and validity and reliability of this research. Unfortunately, a limitation of this study is that a measure for social support was not utilized, as it was only determined that this might be a variable of high importance following the initial launch of data collection. However, the collection of a wealth of sociodemographic variables allowed for an informal measure of social support to be used in analyzing data. While this study's psychometric measures of health-related quality of life and emotion regulation were well-validated, one commonly reported limitation of self-report measures are their subjectivity. Additionally, the SF-12 HS had a low reliability, contrary to previous research on the measure, this would unfortunately attenuate the above findings. Emotion regulation was the focal variable of interest and measured using self-report as opposed to observer report, or biometric data. Given emotion regulation, especially as it relates to internalization of emotion and one's overall perception of health-related quality of life, is subjective – the hope is that a self-report of experiences adequately captures the construct, however, there is no way to ascertain this without either observer or biometric data. Additionally, the DERS primarily assesses the degree to which the presence or absence of difficulties in emotion regulating negative emotions present, with the regulation of positive emotions unaccounted for. As such, it might be pertinent to include the regulation of positive emotions in future research within emotion regulation of those with MS (Weiss et al., 2015). Additionally, given the primary source of data was self-report questionnaires, there is potential for response bias in terms of socially desirable responding.

There is a lack of control group in this study, lending itself to less causational conclusions. Future studies of emotion regulation in those with MS should certainly

include collection of control group data, in order to ascertain whether any findings within the MS group are specific to those with MS. Additionally, this study is cross-sectional in nature – limiting the ability to make conclusions surrounding whether the results would be consistent over a period of time, as well as whether emotion regulation and HRQOL co-vary across time. Ideally, a larger sample size would allow for more statistical power and sensitivity to small effect sizes, given only large-medium effects were detectable with the obtained sample size of 54 participants. Additionally, approximately half of the sample did self-report their diagnosis of MS, meaning there is a concern of inaccurate reporting of diagnosis and subtype of MS. As with any research, a complete data set without missing data would be optimal for analyses, unfortunately, this study was unable to produce a complete dataset, with significant data having to be managed using multiple imputation method. Finally, there are likely other variables that were not included in the regression models that might account for some of the relationship observed between variables of interest (e.g., coping skills, interventions to date, personality).

5.4 Clinical Implications & Future Directions

People with MS often present with a diverse and variable set of symptoms that consist of physical, cognitive, and mental difficulties. No one etiology has been identified in the diagnosis of MS, making the disease progression uncertain with significant levels of disability associated with a diverse set of symptoms. Due to the heterogeneity of the disease, the revised Wilson & Cleary model of health-related quality of life allows for a nuanced conceptual understanding of the many types of variables (i.e., symptoms, functional status) in combination that impact an individual's perspective of their overall health and wellbeing. Given emotion regulation can be both a neurological consequence

of the disease, as well as a psychological consequence of living with the neurodegenerative disease due to identity reformation, loss of economic stability, and adaptive decline – both individual and environmental factors are involved in HRQOL of those with MS. Research has identified some environmental (e.g., social support) and stable individual factors (e.g., age and gender) that might influence general health perceptions, particularly within the MS population. However, the current study aims to provide a better understanding of the possible influence of dynamic psychological individual characteristics (i.e., emotion regulation) that have the potential to be targeted for clinical intervention, creating clinically meaningful change in quality of life.

Emotion dysregulation has been identified as a transdiagnostic construct of importance across many mental health conditions such as eating disorders, anxiety, depression, and substance use disorders (Aldao et al., 2010; Sloan et al., 2017). Furthermore, research into applying treatment of emotion dysregulation for individuals with personality disorders (e.g., Borderline Personality Disorder), and neuro-developmental disorders (e.g., Attention-Deficit/Hyperactivity Disorder and Autism Spectrum Disorder) has been particularly promising (Vasiljevic et al., 2022; Waxmonsky et al., 2021).

Limited research has been pursued in applying emotion regulation interventions in treatment with those with primary physical cause to their symptom profiles of emotion dysregulation. However, there have been a select few studies that have started to examine the use of psychological interventions for patients with MS. More and more research has started to emphasize the importance of transdiagnostic treatments in psychological interventions, with pharmacological treatment also having their standard of care as

transdiagnostic (Chapron et al., 2022; Newby et al., 2015). In particular within North America, the use of intervention to maintain emotional stability in individuals with co-morbid depression has been explored with cognitive behavioural therapy (CBT) showing the greatest promise followed by pharmacotherapy (Chwastiak & Ehde, 2007). In addition to CBT based interventions, psychological treatment that targets emotion dysregulation specifically has also been recently found to have promising outcomes for those with MS. In 2020, Nazari et al. completed a single blind randomized control trial with 70 Persian patients with MS who were assigned to either receive a psychoeducation-based treatment as usual, or therapy using the Unified Protocol of Transdiagnostic Treatment of Emotion Disorder. Promisingly, those who received transdiagnostic treatment demonstrated positive treatment outcomes as measured by the DERS, compared to treatment as usual (Nazari et al., 2020). Most recently, treatment of emotion dysregulation in patients with MS has shown to be promising in two separate randomized control trials (Lancaster et al., 2022; Hughes et al., 2022). Lancaster and colleagues (2022), noted that treatment of emotion dysregulation using only six sessions of interpersonally focused emotion regulation skills training resulted in a decrease in depressive symptomology. In another recent study, Hughes and colleagues (2022) conducted a pilot randomized trial of 20 patients with MS and their partners found that dialectical behaviour therapy (DBT) skills training significantly reduced anxiety and depression symptoms, with some reduction in overall emotion dysregulation that is approaching significance. In sum, while there have not been many studies completed on the efficacy of emotion regulation targeted treatment for those with MS and co-morbid emotion dysregulation profiles, it appears that there is promise in pursuing this avenue.

The current study adds to these treatment studies by further supporting the need to provide emotion regulation interventions to help those with MS to improve their HRQOL.

In the future, Canadian research examining the use of psychological interventions for those with MS and emotion dysregulation concerns would certainly be pertinent, especially given the high rates of MS within North America. Following the completion of additional research in emotion regulation interventions, it will be important to further expand into understanding the shorter-term and longer-term effectiveness of treatments, especially as symptoms progress. Further research into the efficacy of psychological emotion regulation interventions compared to commonly used pharmacotherapy would also be important, as well as how to effectively integrate caregivers into treatment. The current study has identified emotion dysregulation as a dynamic construct that has a significant impact on the MHRQOL of patients with MS; therefore, further research into treatment and support for those with MS and a co-morbid emotion dysregulation profile should be pursued longitudinally with larger samples.

References

Aldao, A., Nolen-Hoeksema, S., & Schweizer, S. (2010). Emotion-regulation strategies across psychopathology: A meta-analytic review. *Clinical psychology review*, *30*(2), 217-237. https://doi.org/10.1016/j.cpr.2009.11.004

Alsayed, N. S., Sereika, S. M., Albrecht, S. A., Terry, M. A., & Erlen, J. A. (2017). Testing a model of health-related quality of life in women living with HIV infection. *Quality of Life Research, 26*(3), 655-663. https://doi.org/10.1007/s11136-016-1482-4

Amankwah, N., Marrie, R. A., Bancej, C., Garner, R., Manuel, D.G., Wall, R., Fines, P., Bernier, J., Tu, K., & Reimer, K. (2017). Multiple Sclerosis in Canada 2011 to 2031: Results of a microsimulation modelling study of epidemiological and economic impacts. *Health Promotion and Chronic Disease in Canada, 37*(2), 37-48. https:// doi: 10.24095/hpcdp.37.2.02.

Amtmann, D., Bamer, A. M., Kim, J., Chung, H., & Salem, R. (2017). People with Multiple Sclerosis report significantly worse symptoms and health related quality of life than the US general population as measured by PROMIS and NeuroQoL outcome measures. *Disability and Health Journal*, *11*(1), 99-107. https://doi.org/10.1016/j.dhjo.2017.04.008

Ascherio, A., & Munger, K. (2007). Environmental risk factors for multiple sclerosis. Part I: The role of infection. *Annals of Neurology*, *61*(4), 288-299. https://doi.org/10.1002/ana.21117

Bagozzi, R. P. & Pieters, R. (1998). Goal-directed emotions. *Cognitions and Emotion, 12*(1), 1-26. https://doi.org/10.1080/0269998379754

Bakas, T., McLennon, S. M., Carpenter, J. S., Buelow, J. M., Otte, J. L., Hanna, K. M., Ellett, M. L., Hadler, K. A., & Welch, J. L. (2012). Systematic review of health-related quality of life models. *Health and quality of life outcomes*, *10*, 134. https://doi.org/10.1186/1477-7525-10-134

Baumstarck, K., Pelletier, J., Boucekine, M., & Auquier, P. (2015). Predictors of quality of life in patients with relapsing-remitting multiple sclerosis: A 2-year longitudinal study. *Revue Neurologique*, *171*(2), 173-180. https://doi.org/10.1016/j.neurol.2014.09.005

Beck, C., Metz, L., Svenson, L., & Patten, S. (2005). Regional variation of Multiple Sclerosis prevalence in Canada. *Multiple Sclerosis, 11*, 516-519. https://doi.org/10.1191/1352458505ms1192oa

Berrigan, L. I., Fisk, J. D., Patten, S. B., Tremlett, H., Wolfson, C., Warren, S., Fiest, K. M., McKay, K. A., Marrie, R. A., & CIHR Team in the Epidemiology and Impact of Comorbidity on Multiple Sclerosis (ECoMS) (2016). Health-related quality of life in multiple sclerosis: Direct and indirect effects of comorbidity. *Neurology*, *86*(15), 1417-1424. https://doi.org/10.1212/WNL.0000000000002564

Berking, M., & Wupperman, P. (2012). Emotion regulation and mental health: recent findings, current challenges, and future directions. *Current opinion in psychiatry*, *25*(2), 128-134. https://doi.org/10.1097/YCO.0b013e3283503669

Bertrams, J., Kuwert, E., & Liedtke, U. (1972). HL-A Antigens and Multiple Sclerosis. *Tissue Antigens*, *2*(6), 405-408. https://doi.org/10.1111/j.1399-0039.1972.tb00060.x

Biernacki, T., Sandi, D., Kincses, Z. T., Füvesi, J., Rózsa, C., Mátyás, K., Vécsei, L., & Bencsik, K. (2019). Contributing factors to health-related quality of life in multiple sclerosis. *Brain and Behavior*, *9*(12), 1-9. https://doi.org/10.1002/brb3.1466

Browne, P., Chandraratna, D., Angood, C., Tremlett, H., Baker, C., Taylor, B.V., & Thompson, A.J. (2014). Atlas of Multiple Sclerosis 2013: A growing global problem with widespread inequity. *Neurology 83*(11), 1022-1024. https://doi: 10.1212/WNL.0000000000000768.

Bužgová, R., Kozáková, R., & Škutová, M. (2020). Factors influencing health-related quality of life of patients with multiple sclerosis and their caregivers. *European Neurology, 83*, 380-388. https://doi.org/10.1159/000508949

Campbell, J., Ghushchyan, V., McQueen, R., Cahoon-Metzger, S., Livingston, T., & Nair, K. (2013). Generic quality of life burden of multiple sclerosis as compared to other debilitating chronic conditions. *Value in Health*, *16*(3), 106. https://doi.org/10.1016/j.jval.2013.03.503

Can Demirdöğen, B. (2019). Potential role of calcifying nanoparticles in the etiology of multiple sclerosis. *Medical Hypotheses, 128*, 25-27. https://doi.org/10.1016/j.mehy.2019.05.005

Carvalho, T., Sousa-Mendes, A., Gomes, C., & Guedes, C. (2021). Understanding stress in patients with multiple sclerosis: The joint predictive role of disease characteristics and emotion regulation processes. *European Psychiatry*, *64*(1), 464-465. https://doi.org/10.1192/j.eurpsy.2021.1241

Casetta, I., Riise, T., Nortvedt, M.W., Economou, N.T., De Gennaro, R., Fazio, P, Cesnik, E., Govoni, V. & Granieri, E. (2009). Gender differences in health-related quality of life in multiple sclerosis. *Multiple Sclerosis Journal, 15*(11), 1339-1346. https://doi.org/10.1177/1352458509107016

Cederberg, K.L., Jeng, B., Sasaki, J. E., Braley, T. J., Walters, A. S., & Motl, R. W. (2020). Restless legs syndrome and health-related quality of life in adults with multiple sclerosis. *Journal of Sleep Research*, *29*(3), 12880–. https://doi.org/10.1111/jsr.12880

Chapron, S., Nourredine, M., Dondé, C., Haesebaert, F., Micoulaud-Franchi, J., Geoffroy, P. A., & Rolland, B. (2022). Efficacy and safety of topiramate for reducing impulsivity: A transdiagnostic systematic review and meta-analysis of a common clinical use. *Fundamental & Clinical Pharmacology*, *36*(1), 4-15. https://doi.org/10.1111/fcp.12710

Chwastiak, L. A., & Ehde, D. M. (2007). Psychiatric issues in multiple sclerosis. *The Psychiatric clinics of North America*, *30*(4), 803-817. https://doi.org/10.1016/j.psc.2007.07.003

Chekani, F., Bali, V., & Aparasu, R. R. (2016). Functional status of elderly nursing home residents with Parkinson's disease. *Journal of Parkinson's disease, 6*(3), 617-624. https://doi.org/10.3233/JPD-160822

Christiansen, L., Sanmartin Berglund, J., Lindberg, C., Anderberg, P., & Skär, L. (2019). Health-related quality of life and related factors among a sample of older people with cognitive impairment. *Nursing open*, *6*(3), 849-859. https://doi.org/10.1002/nop2.265

Cohen, J. (1988). Statistical Power Analysis for the Behavioral Sciences (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates, Publishers.

Cotsapas, C., & Mitrovic, M. (2018). Genome-wide association studies of multiple sclerosis. *Clinical & Translational Immunology, 7*(6), 1-9. https://doi.org/10.1002/cti2.1038

Compston, A., & Coles, A. (2008). Multiple Sclerosis. *The Lancet, 372* (9648), 1502-1517. https://doi.org/10.1016/S0140-6736(08)61620-7

Connell, T., Paterson, J., Roberts, R. M., Raghavendra, P., Sawyer, M., & Russo, R. N. (2018). Clinician modifiable factors associated with better quality of life in children with acquired brain injury undergoing rehabilitation. *Brain Injury, 32*(4), 423-430. https://doi.org/10.1080/02699052.2018.1429661

Costa, D., Sá, M., & Calheiros, J. (2012). The effect of social support on the quality of life of patients with multiple sclerosis. *Arquivos de Neuro-Psiquiatria*, *70*(2), 108-113. https://doi.org/10.1590/S0004-282X2012000200007

Coyle, P. K. (2021). What can we learn from sex differences in MS? *J Pers Med, 11*(10), 1006. https://doi.org/ 10.3390/jpm11101006

Cree, B.A.C., Arnold, D. L., Chataway, J., Chitnis, T., Fox, R. J., Pozo Ramajo, A., Murphy, N., & Lassmann, H. (2021). Secondary Progressive Multiple Sclerosis. *Neurology, 97*(8), 378-388. https://doi.org/10.1212/WNL.0000000000012323

Davis, B.E., Lakin, L., Binns, C.C., Currie, K. M., & Rensel, M.R. (2021). Patient and provider insights into the impact of multiple sclerosis on mental health: A narrative review. *Neurology and Therapy 10***,** 99-119. https://doi.org/10.1007/s40120-021-00240-9

De Oliveira, M., Gianeti, T. M. R., Da Rocha, F. C. G., Lisboa-Filho, P. N., & Piacenti-Silva, M. (2020). A preliminary study of the concentration of metallic elements in the blood of patients with Multiple Sclerosis as measured by ICP-MS. *Scientific Reports, 10*(1)*,* 13112-13112. https://doi.org/10.1038/s41598-020-69979-9

Dean, G., McLoughlin, H., Brady, R. et al. (1976). Multiple Sclerosis among immigrants in Greater London. *BMJ, 1*(6014), 861-864. https://doi.org/10.1136/bmj.1.6014.861

Degelman, M. L., & Herman, K. M. (2017). Smoking and multiple sclerosis: A systematic review and meta-analysis using the Bradford Hill criteria for causation. *Multiple Sclerosis and Related Disorders, 17*, 207-216. https://doi.org/10.1016/j.msard.2017.07.020

Dong, Y., & Peng, C. Y. (2013). Principled missing data methods for researchers. *SpringerPlus*, *2*(1), 222. https://doi.org/10.1186/2193-1801-2-222

Duangchan, C., & Matthews, A. K. (2021). Application of Ferrans et al.'s conceptual model of health-related quality of life: A systematic review. *Research in Nursing & Health*, *44*(3), 490-512. https://doi.org/10.1002/nur.22120

Eisenberg, N., & Spinrad, T. L. (2004). Emotion-related regulation: Sharpening the definition. *Child development*, *75*(2), 334-339. https://doi.org/10.1111/j.1467-8624.2004.00674.x

Eizaguirre, M.A., Yastremiz, C., Ciufia, N., Roman, M.R., Alonso, R., Silva, B.A., Garcea, O., Cáceres, F., & Vanotti, S. (2023). Relevance and Impact of Social Support on Quality of Life for Persons With Multiple Sclerosis. *Int J MS Care* 25 (3): 99–103. https://doi.org/10.7224/1537-2073.2022-012

Elian, M., Nightingale, S., Dean, G. (1990). Multiple Sclerosis among United Kingdom-born children of immigrants from the Indian subcontinent, Africa and the West Indies. *Journal of Neurology, Neurosurgery and Psychiatry, 53*(10), 906-911. https://doi.org/10.1136/jnnp.53.10.906

Eyler, A. E., Wilcox, S., Matson-Koffman, D., Evenson, K. R., Sanderson, B., Thompson, J., Wilbur, J., & Rohm-Young, D. (2002). Correlates of physical activity among women from diverse racial/ethnic groups. *Journal of women's health & gender-based medicine*, *11*(3), 239-253. https://doi.org/10.1089/152460902753668448

Ezra, Y., Hammerman, O., & Shahar, G. (2019). The four-cluster spectrum of mind-body interrelationships: An integrative model. *Frontiers in Psychiatry*, *10*, 39. https://doi.org/10.3389/fpsyt.2019.00039

Fagnani, C., Neale, M. C., Nisticò, L., Stazi, M. A., Ricigliano, V. A., Buscarinu, M. C., Salvetti, M., & Ristori, G. (2015). Twin studies in multiple sclerosis: A meta-estimation of heritability and environmentality. *Multiple sclerosis*, *21*(11), 1404-1413. https://doi.org/10.1177/1352458514564492

Faraclas, E., Lynn, J., Lau, J.D. & Mero, A. (2022). Health-related quality of life in people with Multiple Sclerosis: How does this population compare to population-based norms in different health domains? *Journal of Patient Reported Outcomes*, *6*, 12. https://doi.org/10.1186/s41687-022-00415-4

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior research methods*, *39*(2), 175-191. https://doi.org/10.3758/bf03193146

Faul, F., Erdfelder, E., Buchner, A. & Lang, A.G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods 41,* 1149-1160. https://doi.org/10.3758/BRM.41.4.1149

Ferda, C.G., & Gurel, G. (2020). Difficulties in emotion regulation and quality of life in patients with acne. *Quality of Life Research, 29*(2), 431-438. http://dx.doi.org/10.1007/s11136-019-02318-2

Ferrans, C. E., Zerwic, J. J., Wilbur, J. E., & Larson, J. L. (2005). Conceptual model of health-related quality of life. *Journal of nursing scholarship: An official publication of Sigma Theta Tau International Honor Society of Nursing*, *37*(4), 336-342. https://doi.org/10.1111/j.1547-5069.2005.00058.x

Fino, E., Russo, P. M., Tengattini, V., Bardazzi, F., Patrizi, A., & Martoni, M. (2021). Individual differences in emotion dysregulation and social anxiety discriminate between high vs. low quality of life in patients with mild psoriasis. *Journal of Personalized Medicine*, *11*(11), 1236-. https://doi.org/10.3390/jpm11111236

Fordham, B.A., Nelson, P., Griffiths, C.E., & Bundy, C. (2015). The acceptability and usefulness of mindfulness-based cognitive therapy for people living with psoriasis: A qualitative study. *Journal of Dermatology, 172*(3), 823-825.

Forstmann, M., Burgmer, P., & Mussweiler, T. (2012). "The mind is willing, but the flesh is weak": The effects of mind-body dualism on health behavior. *Psychological Science*, *23*(10), 1239-1245. https://doi.org/10.1177/0956797612442392

Frederickson, J. J., Messina, I., & Grecucci, A. (2018). Dysregulated Anxiety and Dysregulating Defenses: Toward an Emotion Regulation Informed Dynamic Psychotherapy. *Frontiers in Psychology*, *9*, 2054-2054. https://doi.org/10.3389/fpsyg.2018.02054

Gedik, Z. (2020). Health-related quality of life in multiple sclerosis: Links to mental health, self-esteem, and self-compassion. *Düşünen Adam The Journal of Psychiatry and Neurological Sciences*, *33*(1), 59-70.

https://doi.org/10.14744/DAJPNS.2019.00061

Gilmour, H., Ramage-Morin, P.L., Wong, S.L. (2018). Multiple sclerosis: Prevalence and Impact. *Health Reports, 29*(1), 3-8.

Giovannoni, G. (2004). Management of secondary-progressive multiple sclerosis. *CNS Drugs*, *18*(10), 653-669.

https://doi.org/10.2165/00023210-200418100-00003

Goodwin, E., Green, C., & Hawton, A. (2020). What difference does it make? A comparison of health state preferences elicited from the general population and from people with Multiple Sclerosis. *Value in Health*, *23*(2), 242–250.

https://doi.org/10.1016/j.jval.2019.08.009

Grassi, M., Nucera, A., & European Community Respiratory Health Study Quality of Life Working Group (2010). Dimensionality and summary measures of the SF-36 v1.6: Comparison of scale- and item-based approach across ECRHS II adults population. *Value in health: The journal of the International Society for Pharmacoeconomics and Outcomes Research*, *13*(4), 469-478.

https://doi.org/10.1111/j.1524-4733.2009.00684.x

Gratz, K. L., & Roemer, L. (2004). Multidimensional assessment of emotion regulation and dysregulation: Development, factor structure, and initial validation of the difficulties in emotion regulation scale. *Journal of Psychopathology and Behavioral Assessment*, *26*(1), 41-54.

https://doi.org/10.1023/B:JOBA.0000007455.08539.94

Grecucci, A., Messina, I., Amodeo, L., Lapomarda, G., Crescentini, C., Dadomo, H., & Panzeri, M. (2020). A dual route model for regulating emotions: Comparing models, techniques and biological mechanisms. *Frontiers in Psychology, 11*, 930-. https://doi.org/10.3389/fpsyg.2020.00930

Gross, J. J. (1998). The emerging field of emotion regulation: An integrative review. *Review of General Psychology, 2*, 271-299.

Gross, J. J. (2014). Handbook of Emotion Regulation. The Guilford Press.

Gross, J. J. (2015). Emotion regulation: Current status and future prospects. *Psychological Inquiry, 26*(1), 1-36. https://doi.org/10.1080/1047840X.2014.940781

Hagell, P., & Westergren, A. (2011). Measurement properties of the SF-12 health survey in Parkinson's disease. *Journal of Parkinson's disease*, *1*(2), 185-196. https://doi.org/10.3233/JPD-2011-11026

Harel, Y., Barak, Y., & Achiron, A. (2007), Dysregulation of affect in multiple sclerosis: New phenomenological approach. *Psychiatry and Clinical Neurosciences, 61*(1), 94-98. https://doi.org/10.1111/j.1440-1819.2007.01616.x

Hermann, B. P., Vickrey, B., Hays, R. D., Cramer, J., Devinsky, O., Meador, K., Perrine, K., Myers, L. W., & Ellison, G. W. (1996). A comparison of health-related quality of life in patients with epilepsy, diabetes and multiple sclerosis. *Epilepsy Research*, *25*(2), 113-118. https://doi.org/10.1016/0920-1211(96)00024-1

Hincapie-Zapata, M. E., Suarez-Escudero. J. C., Pineda-Tamayo, R., & Anaya, J. M. (2009). Quality of life in multiple sclerosis and other chronic autoimmune and non-autoimmune diseases. *Review of Neurology, 48*(5), 225-230. https://doi.org/10.33588/rn.4805.2008288

Housley, W. J., Pitt, D., & Hafler, D. A. (2015). Biomarkers in multiple sclerosis. *Clinical Immunology, 161*(1), 51-58. https://doi.org/10.1016/j.clim.2015.06.015

Hughes, A.J., Botanov, Y., & Beier, M. (2022). Dialectical behavior therapy skills training for individuals with multiple sclerosis and their support partners: A pilot randomized controlled trial. *Multiple Sclerosis and Related Disorders*, *59*, 103481-103481. https://doi.org/10.1016/j.msard.2021.103481

Ille, R., Wabnegger, A., Schwingenschuh, P., Katschnig-Winter, P., Kögl-Wallner, M., Wenzel, K., & Schienle, A. (2015). Intact emotion recognition and experience but dysfunctional emotion regulation in idiopathic Parkinson's Disease. *Journal of the neurological sciences*, *361*, 72–78. https://doi.org/10.1016/j.jns.2015.12.007.

Innamorati, M., Quinto, R. M., Imperatori, C., Lora, V., Graceffa, D., Fabbricatore, M., Lester, D., Contardi, A., & Bonifati, C. (2016). Health-related quality of life and its association with alexithymia and difficulties in emotion regulation in patients with psoriasis. *Comprehensive Psychiatry*, *70*, 200-208. https://doi.org/10.1016/j.comppsych.2016.08.001

Jacobs, B. M., Giovannoni, G., Cuzick, J., & Dobson, R. (2020). Systematic review and meta-analysis of the association between Epstein–Barr virus, multiple sclerosis and other risk

factors. *Multiple Sclerosis, 26*(11), 1281-1287. https://doi.org/10.1177/1352458520907901

Jongen, P. (2017). Health-related quality of life in patients with multiple sclerosis: Impact of disease-modifying drugs. *CNS Drugs*, *31*(7), 585-602. https://doi.org/10.1007/s40263-017-0444-x

Kerbrat, A., Hamonic, S., Leray, E., Tron, I., Edan, G., Yaouanq, J. (2015). Ten-year prognosis in multiple sclerosis: A better outcome in relapsing−remitting patients but not in primary progressive patients. *European Journal of Neurology*, *22*(3), 507-535. https://doi.org/10.1111/ene.12600

Kever, A., Buyukturkoglu, K., Riley, C. S., De Jager, P. L., & Leavitt, V. M. (2021). Social support is linked to mental health, quality of life, and motor function in Multiple Sclerosis. *Journal of Neurology*, *268*(5), 1827-1836. https://doi.org/10.1007/s00415-020-10330-7

Kim, J. H. (2019). Multicollinearity and misleading statistical results. *Korean Journal of Anesthesiology, 72*(6), 558-569. https://doi.org/10.4097/kja.19087

Kingwell, E., Leung, A. L., Roger, E., Duquette, P., Rieckmann, P., & Tremlett, H. (2010). Factors associated with delay to medical recognition in two Canadian multiple sclerosis cohorts. *Journal of the Neurological Sciences, 292*(1), 57-62. https://doi.org/10.1016/j.jns.2010.02.007

Klineova, S., & Lublin, F. D. (2018). Clinical course of Multiple Sclerosis. *Cold Spring Harbor Perspectives in Medicine, 8*(9). https://doi.org/10.1101/cshperspect.a028928

Kovac, A., Tovilovic, S., Bugarski-Ignjatovic, V., Popovic-Petrovic, S., & Tatic, M. (2018). The role of cognitive emotion regulation strategies in health related quality of life of breast cancer patients. *Vojnosanitetski Pregled*, *77*(10), 178. https://doi.org/10.2298/VSP180205178K

Kurtzke, J.F., Beebe, G.W., & Norman, J.E. (1985). Epidemiology of multiple sclerosis in US veterans: III. Migration and the risk of MS. *Neurology, 35*(5), 672-678. https://doi.org/10.1212/wnl.35.5.672

Kuspinar, A., Rodriguez, A. M. & Mayo, N. E. (2012). The effects of clinical interventions on health related quality of life in Multiple Sclerosis: A meta-analysis. *Multiple Sclerosis Journal, 18*(12), 1686-1704. https://doi.org/10.1177/13524558512445201

Lancaster, K., Thomson, S.J., Chiaravolloti, N.D., & Genova, H.M. (2022). Improving mental health in Multiple Sclerosis with an interpersonal emotion regulation intervention: A prospective, randomized controlled trial. *Clinical Trial, 60*, 103643. https://doi.org/10.1016/j.msard.2022.103643

Lazarus, R.S. (1993). From psychological stress to the emotions: A history of changing outlooks. *Annual Review of Psychology, 44*(1), 1-22. https://doi.org/10.1146/annurev.ps.44.020193.000245

Lebrun, C., Bensa, C., Debouverie, M., Wiertlevski, S., Brassat, D., de Seze, J., Rumbach, L., Pelletier, J., Labauge, P., Brochet, B., Tourbah, A., Clavelou, P., & Club Francophone de la Sclérose en Plaques. (2009). Association between clinical conversion to Multiple Sclerosis in radiologically isolated syndrome and magnetic resonance imaging,

cerebrospinal fluid, and visual evoked potential: Follow-up of 70 patients. *Archives of neurology*, *66*(7), 841–846. https://doi.org/10.1001/archneurol.2009.119

Little, R. J. A., & Rubin, D. B. (2002). Statistical Analysis with Missing Data. Hoboken, NJ: John Wiley & Sons. http://dx.doi.org/10.1002/9781119013563

Löffler, L., Radke, S., Morawetz, C., & Derntl, B. (2016). Emotional dysfunctions in neurodegenerative diseases. *Journal of Comparative Neurology*, *524*(8), 1727–1743. https://doi.org/10.1002/cne.23816

Lublin, F. D., & Reingold, S. C. (1996). Defining the clinical course of multiple sclerosis: results of an international survey. National Multiple Sclerosis Society (USA) advisory committee on clinical trials of new agents in Multiple Sclerosis. *Neurology*, *46*(4), 907–911. https://doi.org/10.1212/wnl.46.4.907

Lublin, F. D, Reingold, S. C, Cohen, J. A, Cutter, G. R, Sorensen, P. S, Thompson, A. J, . . . Polman, C. H. (2014). Defining the clinical course of Multiple Sclerosis: The 2013 revisions. *Neurology, 83*(3), 278-286. https://doi.org/10.1212/WNL.0000000000000560

Madireddy, L., Patsopoulos, N., Cotsapas, C., Bos, S., Beecham, A., McCauley, J., Kim, K., Jia, X., Santaniello, A., Caillier, S., Andlauer, T., Barcellos, L., Berge, T., Bernardinelli, L., Martinelli-Boneschi, F., Booth, D., Briggs, F., Celius, E., Comabella, M., … Dedham, K. (2019). A systems biology approach uncovers cell-specific gene regulatory effects of genetic associations in multiple sclerosis. *Nature Communications, 10*(1), 2236.

https://doi.org/10.1038/s41467-019-09773-y

Marrie, R. A., Fisk, J., Stadnyk, K., Yu, B., Tremlett, H., Wolfson, C., Warren, S. & Bhan, V. (2013). The incidence and prevalence of Multiple Sclerosis in Nova Scotia, Canada. *Canadian Journal of Neurological Sciences, 40*(6), 824-831. https://doi.org/10.1017/S0317167100015961

Marrie, R. A., Reingold, S., Cohen, J., Stuve, O., Trojano, M., Sorensen, P. S., Cutter, G., & Reider, N. (2015a). The incidence and prevalence of psychiatric disorders in Multiple Sclerosis: A systematic review. *Multiple sclerosis*, *21*(3), 305–317. https://doi.org/10.1177/1352458514564487

Marrie, R. A., Fisk, J. D., Tremlett, H., Wolfson, C., Warren, S., Tennakoon, A., Leung, S. & Patten, S. B. (2015b). Differences in the burden of psychiatric comorbidity in MS vs the general population. *Neurology, 85* (22), 1972-1979. https://doi.org/10.1212/WNL.0000000000002174

Márki, G., Bokor, A., Rigó, J., & Rigó, A. (2017). Physical pain and emotion regulation as the main predictive factors of health-related quality of life in women living with endometriosis. *Human Reproduction*, *32*(7), 1432–1438. https://doi.org/10.1093/humrep/dex091

Mayo, N.E., Scott, S.C., Bayley, M. Cheung, A., Garland, J., Jutai, J., & Wood-Dauphinee, S. (2015). Modeling health-related quality of life in people recovering from stroke. *Quality of Life Research, 24,* 41–53. https://doi.org/10.1007/s11136-013-0605-4

McCabe, M. P., & McKern, S. (2002). Quality of life and Multiple Sclerosis: Comparison between people with Multiple Sclerosis and people from the general population. *Journal*

of Clinical Psychology in Medical Settings, *9*(4), 287–295. https://doi.org/10.1023/A:1020734901150

McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health education quarterly*, *15*(4), 351–377. https://doi.org/10.1177/109019818801500401

Mennin, D. S., Fresco, D. M., O'Toole, M. S., &, Heimberg, R. G. (2018). A randomized controlled trial of emotion regulation therapy for generalized anxiety disorder with and without co-occurring depression. *Journal of Consulting and Clinical Psychology, 86*(3), 268–281. https://doi-org.qe2a-proxy.mun.ca/10.1037/ccp0000289

Menon, S., Zhu, F., Shirani, A., Oger, J., Freedman, M. S., & Tremlett, H. (2017). Disability progression in aggressive Multiple Sclerosis. *Multiple Sclerosis*, *23*(3), 456–463. https://doi.org/10.1177/1352458516653273

Miller, A., & Dishon, S. (2006). Health-related quality of life in multiple sclerosis: The impact of disability, gender and employment status. *Quality of Life Research, 15*(2), 259-271. https://doi.org/10.1007/s11136-005-0891-6

Motl, R., McAuley, E., Wynn, D., Sandroff, B., & Suh, Y. (2013). Physical activity, self-efficacy, and health-related quality of life in persons with Multiple Sclerosis: Analysis of associations between individual-level changes over one year. *Quality of Life Research, 22*(2), 253-261. https://doi.org/10.1007/s11136-012-0149-z

Munger, K., & Ascherio, A. (2011). Prevention and treatment of MS: Studying the effects of vitamin D. *Multiple Sclerosis,17*(12), 1405-1411. https://doi.org/10.1177/1352458511425366

Munger, K.L., Levin, L.I., Hollis, B.W., Howard, N.S., & Ascherio, A. (2006). Serum 25-hydroxyvitamin D levels and risk of Multiple Sclerosis. *The Journal of the American Medical Association, 296*(23), 2832-2838. https://doi.org/10.1001/jama.296.23.2832

Nazari, N., Sadeghi, M., Ghadampour, E. & Mirzaeefar, D. (2020). Transdiagnostic treatment of emotional disorders in people with Multiple Sclerosis: Randomized controlled trial. *BMC Psychology, 8*, 114. https://doi.org/10.1186/s40359-020-00480-8

Newby, J. M., McKinnon, A., Kuyken, W., Gilbody, S., & Dalgleish, T. (2015). Systematic review and meta-analysis of transdiagnostic psychological treatments for anxiety and depressive disorders in adulthood. *Clinical Psychology Review*, *40*, 91–110. https://doi.org/10.1016/j.cpr.2015.06.002

Nokes, K.M., Coleman, C.L., Hamilton, M.J., Corless, I.B., Sefcik, E., Kirksey, K.M., Eller, L.S., Kemppainen, J., Dole, P.J., Nicholas, P.K., Reynolds, N.R., Bunch, E.H., Holzemer, W.L., Wantland, D.J., Tsai, Y.F., Rivero-Mendez, M., & Canaval, G.E. (2011). Age-related effects on symptom status and health-related quality of life in persons with HIV/AIDS. *Applied Nursing Research, 24*(1), 6-10. https://doi.org/ 10.1016/j.apnr.2009.03.002

Okuda, D. T., Mowry, E. M., Beheshtian, A., Waubant, E., Baranzini, S. E., Goodin, D. S., Hauser, S. L., & Pelletier, D. (2009). Incidental MRI anomalies suggestive of Multiple Sclerosis: The radiologically isolated syndrome. *Neurology*, *72*(9), 800–805. https://doi.org/10.1212/01.wnl.0000335764.14513.1a

Ömerhoca, S., Akkaş, S.Y. & İçen, N.K. (2018). Multiple Sclerosis: Diagnosis and differential diagnosis. *Noro Psikiyatr Ars, 55*(1), 1-9. https://doi.org/10.29399/npa.23418

Orgeta V. (2009). Specificity of age differences in emotion regulation. *Aging & mental health*, *13*(6), 818–826. https://doi.org/10.1080/13607860902989661

Oschner, K.N. & Gross, J. J. (2005). The cognitive control of emotion. *Trends in Cognitive Science, 9*(5), 242 – 249. https://doi.org/10.1016/j.tics.2005.03.010

O'Toole, M. S., Mennin, D. S., Applebaum, A., Weber, B., Rose, H., Fresco, D. M., & Zachariae, R. (2019). A randomized controlled trial of emotion regulation therapy for psychologically distressed caregivers of cancer patients. *Journal of the National Cancer Institute Cancer Spectrum, 4*(1). https://doi.org/10.1093/jncics/pkz074

Ozakbas, S., Kaya, D. & Idiman, E. (2012). Early onset Multiple Sclerosis has worse prognosis than adult onset Multiple Sclerosis based on cognition and magnetic resonance imaging. *Autoimmune Diseases*, *2012*, 563989–5. https://doi.org/10.1155/2012/563989

Palimaru, A., & Hays, R. D. (2017). Associations of health-related quality of life with overall quality of life in the patient reported outcomes measurement information system (PROMIS®) project. *Applied Research in Quality of Life*, *12*(2), 241–250. https://doi.org/10.1007/s11482-017-9515-x

Parsons, C. E., Crane, C., Parsons, L. J., Fjorback, L. O., & Kuyken, W. (2017). Home practice in mindfulness-based cognitive therapy and mindfulness-based stress reduction: A systematic review and meta-analysis of participants' mindfulness practice and its association with outcomes. *Behaviour research and therapy*, *95*, 29–41. https://doi.org/10.1016/j.brat.2017.05.004

Patsopoulos, N. A., Bayer Pharma MS Genetics Working Group, Steering Committees of Studies Evaluating IFNβ-1b and a CCR1-Antagonist, ANZgene Consortium, GeneMSA, International Multiple Sclerosis Genetics Consortium, Esposito, F., Reischl, J., Lehr, S., Bauer, D., Heubach, J., Sandbrink, R., Pohl, C., Edan, G., Kappos, L., Miller, D., Montalbán, J., Polman, C. H., Freedman, M. S., Hartung, H. P., … de Bakker, P. I. (2011). Genome-wide meta-analysis identifies novel Multiple Sclerosis susceptibility loci. *Annals of neurology*, *70*(6), 897–912. https://doi.org/10.1002/ana.22609

Pellegrini, F., Copetti, M., Sormani, M., Bovis, F., de Moor, C., Debray, T., & Kieseier, B. (2020). Predicting disability progression in multiple sclerosis: Insights from advanced statistical modeling. *Multiple Sclerosis*, *26*(14), 1828–1836. https://doi.org/10.1177/1352458519887343

Phillips, L. H., Henry, J. D., Nouzova, E., Cooper, C., Radlak, B., & Summers, F. (2014). Difficulties with emotion regulation in Multiple Sclerosis: Links to executive function, mood, and quality of life. *Journal of Clinical and Experimental Neuropsychology*, *36*(8), 831–842. https://doi.org/10.1080/13803395.2014.946891

Ponzia, M., Tacchino, A., Vaccaro, C, Brichetto, G., Battaglia, M. A., & Uccelli, M. M. (2020). Unmet needs influence health related quality of life in people with Multiple Sclerosis. Multiple Sclerosis & Related Disorders, 38, 101877. https://doi.org/10.1016/j.msard.2019.101877

Poppe, A., Wolfson, C., & Zhu, B. (2008). Prevalence of Multiple Sclerosis in Canada: A systemic review. Canadian Journal of Neurological Sciences, 35(5), 593-601. https://doi.org/10.1017/S0317167100009389

Prakash, R., Schirda, B., Valentine, T., Crotty, M., & Nicholas, J. (2019). Emotion dysregulation in Multiple Sclerosis: Impact on symptoms of depression and anxiety. *Multiple Sclerosis and Related Disorders*, *36*, 101399–101399. https://doi.org/10.1016/j.msard.2019.101399

Raymakers, A. J., Carney, P., & Gillespie, P. (2017). An analysis of health-related quality of life in people with Multiple Sclerosis in Ireland. *Value in Health, 20*(9), A725. https://doi.org/10.1016/j.jval.2017.08.1959.

Ritschel, L. A., Tone, E. B., Schoemann, A. M., & Lim, N. E. (2015). Psychometric properties of the Difficulties in Emotion Regulation Scale across demographic groups. *Psychological assessment*, *27*(3), 944–954. https://doi.org/10.1037/pas0000099

Rudick, R. A., Miller, D., Clough, J.D., Gragg, L.A., Farmer, R.G. (1992). Quality of life in Multiple Sclerosis: Comparison with inflammatory bowel disease and rheumatoid arthritis. *Archives of Neurol, 49*(12), 1237–1242. https://doi.org/10.1001/archneur.1992.00530360035014

Sabanagic-Hajric, S., Suljic, E., Memic-Serdarevic, A., Sulejmanpasic, G., & Mahmutbegovic, N. (2022). Quality of Life in Multiple Sclerosis Patients: Influence of Gender, Age and Marital Status. *Mater Sociomed, 34*(1), 19-24. https://doi.org/10.5455/msm.2022.33

Sadeghi Bahmani, D., Razazian, N., Motl, R. W., Farnia, V., Alikhani, M., Pühse, U., Gerber, M., & Brand, S. (2020). Physical activity interventions can improve emotion regulation and dimensions of empathy in persons with Multiple Sclerosis: An exploratory study. *Multiple Sclerosis and Related Disorders*, *37*, 101380. https://doi.org/10.1016/j.msard.2019.101380

Sadovnik, D. (2019). The place of environmental factors in multiple sclerosis: Genes, environment and the interactions thereof in the etiology of multiple sclerosis. *Revue Neurologique, 175*(10), 593-596. https://doi.org/10.1016/j.neurol.2019.08.003

Schapira, K., Poskanzer, D.C., & Miller, H. (1963). Familial and conjugal Multiple Sclerosis. *Brain*, *86*(2), 315–332. https://doi.org/10.1093/brain/86.2.315

Schirda, B., Nicholas, J., & Prakash, R. (2015). Examining trait mindfulness, emotion dysregulation, and quality of life in Multiple Sclerosis. *Health Psychology*, *34*(11), 1107–1115. https://doi.org/10.1037/hea0000215

Schreiber, K., Kant, M., Pfleger, C., Jensen, H. B., Oesterberg, O., Hald, A. R., Nielsen, F. K., & Rubak, S. (2018). High treatment adherence, satisfaction, motivation, and health-related quality of life with fingolimod in patients with relapsing-remitting multiple

sclerosis - results from a 24-month, multicenter, open-label Danish study. *Patient Preference and Adherence*, *12*, 1139–1150. https://doi.org/10.2147/PPA.S166278

Silveira, C., Guedes, R., Maia, D., Curral, R., & Coelho, R. (2019). Neuropsychiatric symptoms of Multiple Sclerosis: State of the art. *Psychiatry Investigation, 16*(12), 877-888. https://doi.org/10.30773/pi.2019.0106

Sintzel, M., Rametta, M., & Reder, A. (2018). Vitamin D and Multiple Sclerosis: A comprehensive review. *Neurology and Therapy*, *7*(1), 59–85. https://doi.org/10.1007/s40120-017-0086-4

Sloan, Hall, K., Moulding, R., Bryce, S., Mildred, H., & Staiger, P. K. (2017). Emotion regulation as a transdiagnostic treatment construct across anxiety, depression, substance, eating and borderline personality disorders: A systematic review. *Clinical Psychology Review*, *57*, 141–163. https://doi.org/10.1016/j.cpr.2017.09.002

Sloka, J. S., Pryse-Phillips, W. E., & Stefanelli, M. (2005). Incidence and prevalence of multiple sclerosis in Newfoundland and Labrador. *The Canadian journal of neurological sciences. Le journal canadien des sciences neurologiques*, *32*(1), 37–42. https://doi.org/10.1017/s0317167100016851

Stern, B., Strober, L., & Goverover, Y. (2020). Relationship between sensory processing patterns, trait anxiety, and health-related quality of life in multiple sclerosis. *Journal of Health Psychology, 00*(0), 1-12. https://doi.org/10.1177/1359105319901316

Tabachnick, B. G., & Fidell, L. S. (2018). Using Multivariate Statistics (7th ed.). Boston, MA: Pearson.

Thompson, A. J., Baranzini, S. E., Geurts, J., Hemmer, B., & Ciccarelli, O. (2018). Multiple sclerosis. *Lancet*, *391*(10130), 1622-1636. https://doi.org/10.1016/S0140-6736(18)30481-1

Trindade, I. A., Ferreira, C. & Pinto-Gouveia, J. (2018). The longitudinal effects of emotion regulation on physical and psychological health: A latent growth analysis exploring the role of cognitive fusion in inflammatory bowel disease. *British Journal of Health Psychology, 23*(1), 171-185. https://doi.org/10.1111/bjhp.12280

Trudel-Fitzgerald, C., Qureshi, F., Appleton, A.A., & Kubzansky, L.D. (2017). A healthy mix of emotions: underlying biological pathways linking emotions to physical health. *Current Opinion in Behavioral Sciences, 15*, 16-21. https://doi.org/10.1016/j.cobeha.2017.05.003

Tsaousides, T., Spielman, L., Kajankova, M., Guetta, G., Gordon, W., Dams-O'Connor, K. & Neumann, D. (2017). Improving emotion regulation following web-based group intervention for individuals with traumatic brain injury. *Journal of Head Trauma Rehabilitation, 32*(5), 354–365. https://doi.org/10.1097/HTR.0000000000000345

Vasiljevic, S., Isaksson, M., Wolf-Arehult, M., Öster, C., Ramklint, M., & Isaksson, J. (2022). Brief internet-delivered skills training based on DBT for adults with borderline personality disorder - a feasibility study. *Nordic Journal of Psychiatry*, 1–10. https://doi.org/10.1080/08039488.2022.2055791

Visser, L. A., Louapre, C., Uyl-de Groot, C. A., & Redekop, W. K. (2021). Health-related quality of life of multiple sclerosis patients: a European multi-country study. *Archives of public health*, *79*(1), 39. https://doi.org/10.1186/s13690-021-00561-z

Wagley, S., Bokori-Brown, M., Morcrette, H., Malaspina, A., D'Arcy, C., Gnanapavan, S., Lewis, N., Popoff, M., Raciborska, D., Nicholas, R., Turner, B., & Titball, R. (2018). Evidence of Clostridium perfringens epsilon toxin associated with Multiple Sclerosis. *Multiple Sclerosis*, *25*(5), 653–660. https://doi.org/10.1177/1352458518767327

Ware, J. E., Kosinski, M., & Keller, S. D. (1996). A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care*, *34*(3), 220–233. https://doi.org/10.1097/00005650-199603000-00003

Waxmonsky, J.G., Baweja, R., Bansal, P. S., & Waschbusch, D. A. (2021). A review of the evidence base for psychosocial interventions for the treatment of emotion dysregulation in children and adolescents. *Child and Adolescent Psychiatric Clinics of North America*, *30*(3), 573–594. https://doi.org/10.1016/j.chc.2021.04.008

Weiss, N. H., Gratz, K. L., & Lavender, J. M. (2015). factor structure and initial validation of a multidimensional measure of difficulties in the regulation of positive emotions: The DERS-positive. *Behavior Modification*, *39*(3), 431–453. https://doi.org/10.1177/014544551456650

White, S., Conner, C., Beck, K., & Mazefsky, C. (2021). Clinical update: The implementation of evidence-based emotion regulation treatment for clients with autism. *Evidence-Based Practice in Child and Adolescent Mental Health*, *6*(1), 1–10. https://doi.org/10.1080/23794925.2020.1796551

Wierenga, K., Fresco, D., Alder, M., & Moore, S. (2021). Feasibility of an emotion regulation intervention for patients in cardiac rehabilitation. *Western Journal of Nursing Research*, *43*(4), 338–346. https://doi.org/10.1177/0193945920949959

Widdifield, J., Ivers, N. M., Young, J., Green, D., Jaakkimainen, L., Butt, D. A., O'Connor, P., Hollands, S., & Tu, K. (2015). Development and validation of an administrative data algorithm to estimate the disease burden and epidemiology of multiple sclerosis in Ontario, Canada. *Multiple Sclerosis*, *21*(8), 1045–1054. https://doi.org/10.1177/1352458514556303

Wilson, I. B., & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life: A conceptual model of patient outcomes. *JAMA*, *273*(1), 59–65. https://doi.org/10.1001/jama.1995.03520250075037

World Health Organization: International Classification of Functioning, Disability, and Health: Children and Youth Version: ICF-CY. Geneva: World Health Organization; 2007.

Wu, N., Minden, S. L., Hoaglin, D. C., Hadden, L., & Frankel, D. (2007). Quality of life in people with Multiple Sclerosis: Data from the Sonya Slifka longitudinal Multiple Sclerosis study. *Journal of Health and Human Services Administration, 30*(3), 233-67.

Wu, C., Yi, Q., Zheng, X., Cui, S., Chen, B., Lu, L., & Tang, C. (2019). Effects of mind-body exercises on cognitive function in older adults: A meta-analysis: mind-body exercises and

cognitive performance. *Journal of the American Geriatrics Society*, *67*(4), 749–758. https://doi.org/10.1111/jgs.15714

Wyrwich, K.W., Harnam, N., Locklear, J.C., Svedsater, H. &, Revicki, D.A. (2011). Understanding the relationships between health outcomes in generalized anxiety disorder clinical trials. *Quality of Life Research, 20,* 255–262. https://doi.org/10.1007/s11136-010-9734-1

Yamout, B., Issa, Z., Herlopian, A., El Bejjani, M., Khalifa, A., Ghadieh, A.S. and Habib, R.H. (2013). Predictors of quality of life among multiple sclerosis patients: a comprehensive analysis. *Eur J Neurol, 20*, 756-764. https://doi.org/10.1111/ene.12046

Zarotti, N., Fletcher, I., & Simpson, J. (2019). New perspectives on emotional processing in people with symptomatic Huntington's Disease: Impaired emotion regulation and recognition of emotional body language. *Archives of Clinical Neuropsychology, 34*(5), 610-624. https://doi.org/10.1093/arclin/acy085

Zinchenko, A., Kanske, P., Obermeier, C., Schroger, E., & Kotz, S. A. (2015). Emotion and goal-directed behaviour: ERP evidence on cognitive and emotional conflict. *Soc Cogn Affect Neurosci, 10*(11), 1577-1587. https://doi/10.1093/scan/nsv050

Appendices

Appendix A

Sociodemographic Questionnaire

End of Block

Demographic Form

Demographic Form

Thank you for agreeing to participate in our research study!

Q87 General Information

Q1 What is your age in years?

Q2 What is your gender?

- ○ Male (1)
- ○ Female (2)
- ○ Other (3) _____

Q3 What is your primary language?

- French (1)
- English (2)
- Other (3)

Q4 What is the highest level of education you have completed?

- Elementary School/Junior High School (1)
- Some High School (2)
- High School (3)
- Vocational/Technical School (2 years) (4)
- College (5)
- University Bachelor's Degree (6)
- Master's Degree (7)
- Professional Degree (PhD, MD, etc.) (8)

Q5 What city, town, or community do you currently live in?

Q6 How long have you lived in your current city, town, or community?

Q7 What is your marital status?

- ○ Divorced (1)
- ○ Living with a partner (2)
- ○ Married (3)
- ○ Separated (4)
- ○ Single (5)
- ○ Widowed (6)

Q9 How many children under 16 years old live in your household?

- ○ None (1)
- ○ 1 (2)
- ○ 2 (3)
- ○ 3 (4)
- ○ 4 or more (5)

Page Break

Q95 Employment and Income

Q8 What is your current household income?

- ○ Under $10,000 (1)
- ○ $10,000 - $19,999 (2)
- ○ $20,000 - $29,999 (3)
- ○ $30,000 - $39,999 (4)
- ○ $40,000 - $49,999 (5)
- ○ $50,000 - $74,999 (6)
- ○ $75,000 - $99,999 (7)
- ○ Over $100,000 (8)

Q10 What is your current employment situation?

- [ ] Unemployed (1)
- [ ] Retired (2)
- [ ] Employed (3)
- [ ] Student (4)
- [ ] Other (5) _____

Q88 What is your employment status?

- ○ Full-time (1)
- ○ Part-time (2)
- ○ Other (3) _____

Display This Question:

If What is your current employment situation? Employed Is Selected

Or What is your current employment situation? Other Is Selected

Q10.2 What is your occupation?

Page Break

Q96 Medical Issues

Q21 Do you currently experience pain in your daily life? If yes, please rate your pain from 0 to 10

	0 (No Pain) (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	10 (Worst pain possible) (11)
Pain rating (1)	○	○	○	○	○	○	○	○	○	○	○

Q103 If you experience pain, please list the location(s) of your pain (e.g. right arm, left leg, front of head, etc.).

Q12 Do you have a medical issue that impacts your daily living?

- ☐ Yes; Multiple Sclerosis (1)
- ☐ Yes; Other (2) _____
- ☐ No (3)

Skip To: Q97 If Q12 = No (3)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Multiple Sclerosis Is Selected

Q15 How old were you when you were first diagnosed with MS?

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Multiple Sclerosis Is Selected

Q15.1 What type of MS do you have?

- ○ Relapsing and Remitting (1)
- ○ Primary Progressive (2)
- ○ Secondary Progressive (3)
- ○ Progressive Relapsing (4)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Multiple Sclerosis Is Selected

Q91 What symptoms related to MS cause you the greatest concern?

- [ ] Physical Impairment (1)
- [ ] Cognitive Decline (2)
- [ ] Depression (3)
- [ ] Anxiety (4)
- [ ] Pain (5)
- [ ] Balance and Dizziness (6)
- [ ] Bladder Dysfunction (7)
- [ ] Fatigue (8)
- [ ] Sensory Impairment, Numbness/ Tingling (9)
- [ ] Tremors (10)
- [ ] Burning Sensation (11)
- [ ] Other (12) _____
- [ ] None (13)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Multiple Sclerosis Is Selected

Q90 How long did you have symptoms before you received your current diagnosis of MS?

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Multiple Sclerosis Is Selected

Q92 Were your symptoms of MS misdiagnosed before receiving your current diagnosis?

- Yes (1)
- No (2)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Multiple Sclerosis Is Selected

Q93 Has your diagnosis of MS impacted your physical functioning? If yes, which limbs have been impacted?

- Yes (1)
- No (2)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Multiple Sclerosis Is Selected

Q11 Has your employment status changed as a result of your diagnosis of MS?

- Yes (1)
- No (2)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Multiple Sclerosis Is Selected

Q26 Do you feel that your personality has changed since the symptoms of MS started?

- Yes (1)
- No (2)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Multiple Sclerosis Is Selected

Or Do you have a medical issue that impacts your daily living? Yes; Other Is Selected

Q143 Please check any of the personality changes that you have experienced since your symptoms of MS first started

- [ ] Social Withdrawal (1)
- [ ] Increased Social Contact (2)
- [ ] Increased Irritability (3)
- [ ] Depressed Mood (4)
- [ ] Increased Anxiety (5)
- [ ] Increased Anger (6)
- [ ] Increased Need for Control Over the People You Live With (7)
- [ ] Increased Procrastination (8)
- [ ] Increased Need For Order and Organization (9)
- [ ] Less Likely to Try New Things (10)
- [ ] Other: (11) _____
- [ ] None (12)

Page Break

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Other Is Selected

Q89 How old were you when you were diagnosed with your non-MS medical issue(s)?

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Other Is Selected

Q136 What symptoms related to your non-MS medical issue(s) cause you the greatest concern?

- ☐ Physical Impairment (1)
- ☐ Cognitive Decline (2)
- ☐ Depression (3)
- ☐ Anxiety (4)
- ☐ Pain (5)
- ☐ Balance and Dizziness (6)
- ☐ Bladder Dysfunction (7)
- ☐ Fatigue (8)
- ☐ Sensory Impairment, Numbness/ Tingling (9)
- ☐ Tremors (10)
- ☐ Burning Sensation (11)
- ☐ Other (12) _____
- ☐ None (13)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Other Is Selected

Q137 How long did you have symptoms before you received your current diagnosis for your non-MS medical issue(s)?

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Other Is Selected

Q138 Were your symptoms of your non-MS medical issue(s) misdiagnosed before receiving your current diagnosis?

- Yes (1)
- No (2)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Other Is Selected

Q139 Has your non-MS medical issue(s) impacted your physical functioning? If yes, which limbs have been impacted?

- Yes (1)
- No (2)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Other Is Selected

Q140 Has your employment status changed as a result of your non-MS medical issue(s)?

- Yes (1)
- No (2)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Other Is Selected

Q142 Do you feel that your personality has changed since the symptoms of the symptoms of your non-MS medical issue started?

- Yes (1)
- No (2)

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Other Is Selected

Q144 Please check any of the personality changes that you have experienced since your symptoms of your non-MS medical issue(s) first started

- ☐ Social Withdrawal (1)
- ☐ Increased Social Contact (2)
- ☐ Increased Irritability (3)
- ☐ Depressed Mood (4)
- ☐ Increased Anxiety (5)
- ☐ Increased Anger (6)
- ☐ Increased Need for Control Over the People You Live With (7)
- ☐ Increased Procrastination (8)
- ☐ Increased Need For Order and Organization (9)
- ☐ Less Likely to Try New Things (10)
- ☐ Other: (11) _____
- ☐ None (12)

Page Break

Q97 Social Support

Q16 Do you feel that you have enough social support?

- Yes (1)
- No (2)

Q17 How many people do you have that you feel that you can count on to support you?

- None (1)
- 1 (2)
- 2 (3)
- 3 (4)
- 4 or more (5)

Page Break

Q98 Psychological Condition

Q18 Have you ever been diagnosed with any of the following psychological conditions?

- ☐ Anxiety (1)
- ☐ Depression (2)
- ☐ ADHD (3)
- ☐ Psychosis (4)
- ☐ Bipolar Depression (5)
- ☐ Other: (6) _____
- ☐ None (7)

Q19 Are you currently being treated for a psychological condition?

- ○ Yes (1)
- ○ No (2)

Display This Question:

If Have you ever been diagnosed with any of the following psychological conditions? None Is Not Selected

Q19.1 How old were you when were you first diagnosed with a psychological condition?

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Multiple Sclerosis Is Selected

Or Do you have a medical issue that impacts your daily living? Yes; Other Is Selected

Q19.2 Were your psychological symptoms diagnosed before your chronic condition?

- Yes (1)
- No (2)

Display This Question:

If Do you have a medical issue that impacts your daily living? No Is Not Selected

Q19.4 Please list your current symptoms (physical and/or psychological):

Page Break

Q99 Medication, Drugs, and Alcohol

Q22 Please list your prescription medications:

Q23 Have you used drugs that are/were not necessary for medical problems?

- ○ Yes (1)
- ○ No (2)

Skip To: Q24 If Q23 = No (2)

Q23.1 Please indicate the drugs you have used.

- [ ] Cannabis (marijuana) (1)
- [ ] Cocaine (2)
- [ ] Hallucinogens (i.e., LSD) (3)
- [ ] Amphetamines (i.e., ritalin) (4)
- [ ] Opiates (i.e., morphine, codeine) (5)
- [ ] Ectasy (6)
- [ ] Barbiturates (downers, phenobarbital) (7)
- [ ] Other: (8) _____

Q23.2 Do you currently use any of these drugs?

- ○ Yes (1)
- ○ No (2)

Q23.3 Please list the drugs that you currently use that are not necessary for medical reasons and the frequency of use (i.e. daily, weekly, social situations, etc.).

Q24 Do you drink alcohol

- ○ Yes (1)
- ○ No (2)

Skip To: Q100 If Q24 = No (2)

Q104 What type of alcohol do you drink?

- ☐ Wine (1)
- ☐ Beer (2)
- ☐ Spirits (3)
- ☐ Coolers (4)
- ☐ Other (5) _____

Q105 Approximately how much alcohol do you drink in a week?

Page Break

Q100 Head Injury

Q25 Have you ever had a head injury?

- ○ Yes (1)
- ○ No (2)

Display This Question:

If Have you ever had a head injury? Yes Is Selected

Q25.1 Did you lose consciousness?

- ○ Yes (1)
- ○ No (2)

Display This Question:

If Have you ever had a head injury? Yes Is Selected

Q25.2 Have you ever been hospitalized due to a head injury?

- ○ Yes (1)
- ○ No (2)

Page Break

Display This Question:

If Do you have a medical issue that impacts your daily living? Yes; Multiple Sclerosis Is Selected

Or Do you have a medical issue that impacts your daily living? Yes; Other Is Selected

Q27 Are there any changes that you have experienced since your symptoms of your chronic condition started that you would like to add?

Appendix B

Difficulties in Emotion Regulation Scale (DERS)

Serenity Programme™ - serene.me.uk - Difficulties in Emotion Regulation Scale (DERS)

1	2	3	4	5
Almost never (0-10%)	Sometimes (11-35%)	About half the time (36-65%)	Most of the time (66-90%)	Almost always (91-100%)

Difficulties in Emotion Regulation Scale (DERS)

Identifier Date

Please indicate how often the following 36 statements apply to you by writing the appropriate number from the scale above (1 – 5) in the box alongside each item.

1	I am clear about my feelings (R)	☐
2	I pay attention to how I feel (R)	☐
3	I experience my emotions as overwhelming and out of control	☐
4	I have no idea how I am feeling	☐
5	I have difficulty making sense out of my feelings	☐
6	I am attentive to my feelings (R)	☐
7	I know exactly how I am feeling (R)	☐
8	I care about what I am feeling (R)	☐
9	I am confused about how I feel	☐
10	When I'm upset, I acknowledge my emotions (R)	☐
11	When I'm upset, I become angry with myself for feeling that way	☐
12	When I'm upset, I become embarrassed for feeling that way	☐

Page **1** of **5**

Serenity Programme™ - serene.me.uk - Difficulties in Emotion Regulation Scale (DERS)

1	2	3	4	5
Almost never (0-10%)	Sometimes (11-35%)	About half the time (36-65%)	Most of the time (66-90%)	Almost always (91-100%)

13	When I'm upset, I have difficulty getting work done	☐
14	When I'm upset, I become out of control	☐
15	When I'm upset, I believe that I will remain that way for a long time	☐
16	When I'm upset, I believe that I'll end up feeling very depressed	☐
17	When I'm upset, I believe that my feelings are valid and important (R)	☐
18	When I'm upset, I have difficulty focusing on other things	☐
19	When I'm upset, I feel out of control	☐
20	When I'm upset, I can still get things done (R)	☐
21	When I'm upset, I feel ashamed with myself for feeling that way	☐
22	When I'm upset, I know that I can find a way to eventually feel better (R)	☐
23	When I'm upset, I feel like I am weak	☐
24	When I'm upset, I feel like I can remain in control of my behaviours (R)	☐
25	When I'm upset, I feel guilty for feeling that way	☐
26	When I'm upset, I have difficulty concentrating	☐
27	When I'm upset, I have difficulty controlling my behaviours	☐

Serenity Programme™ - serene.me.uk - Difficulties in Emotion Regulation Scale (DERS)

1	2	3	4	5
Almost never (0-10%)	Sometimes (11-35%)	About half the time (36-65%)	Most of the time (66-90%)	Almost always (91-100%)

28	When I'm upset, I believe that there is nothing I can do to make myself feel better	☐
29	When I'm upset, I become irritated with myself for feeling that way	☐
30	When I'm upset, I start to feel very bad about myself	☐
31	When I'm upset, I believe that wallowing in it is all I can do	☐
32	When I'm upset, I lose control over my behaviours	☐
33	When I'm upset, I have difficulty thinking about anything else	☐
34	When I'm upset, I take time to figure out what I'm really feeling (R)	☐
35	When I'm upset, it takes me a long time to feel better	☐
36	When I'm upset, my emotions feel overwhelming	☐

Document Version: 1.1
Last Updated: 05 June 2013
Planned Review: 30 June 2018

Privacy - please note - this form does not transmit any information about you or your assessment scores If you wish to keep your results, you must print this document These results are intended as a guide to your health and are presented for educational purposes only They are not intended to be a clinical diagnosis If you are concerned in any way about your health, please consult with a qualified health professional.

Gratz, K.L. & Roemer, E. Multidimensional Assessment of Emotion Regulation and Dysregulation: Development, Factor Structure, and Initial Validation of the Difficulties in Emotion Regulation Scale. Journal of Psychopathology and Behavioral Assessment, 26: 1, pp. 41-54.

Serenity Programme™ - serene.me.uk - Difficulties in Emotion Regulation Scale (DERS)

1	2	3	4	5
Almost never (0-10%)	Sometimes (11-35%)	About half the time (36-65%)	Most of the time (66-90%)	Almost always (91-100%)

SCORING THE DERS

The DERS is a brief, 36-item self-report questionnaire designed to assess multiple aspects of emotional dysregulation. Reverse-scored items are numbered 1, 2, 6, 7, 8, 10, 17, 20, 22, 24 and 34. Higher scores suggest greater problems with emotion regulation. The measure yields a total score (SUM) as well as scores on six sub-scales:

1. Non-acceptance of emotional responses (NONACCEPT)
2. Difficulties engaging in goal directed behaviour (GOALS)
3. Impulse control difficulties (IMPULSE)
4. Lack of emotional awareness (AWARE)
5. Limited access to emotion regulation strategies (STRATEGIES)
6. Lack of emotional clarity (CLARITY)

1: Nonacceptance of Emotional Responses (NONACCEPT)

25) When I'm upset, I feel guilty for feeling that way
21) When I'm upset, I feel ashamed with myself for feeling that way
12) When I'm upset, I become embarrassed for feeling that way
11) When I'm upset, I become angry with myself for feeling that way
29) When I'm upset, I become irritated with myself for feeling that way
23) When I'm upset, I feel like I am weak

2: Difficulties Engaging in Goal-Directed (GOALS)

26) When I'm upset, I have difficulty concentrating
18) When I'm upset, I have difficulty focusing on other things
13) When I'm upset, I have difficulty getting work done
33) When I'm upset, I have difficulty thinking about anything else
20) When I'm upset, I can still get things done (R)

1	2	3	4	5
Almost never (0-10%)	Sometimes (11-35%)	About half the time (36-65%)	Most of the time (66-90%)	Almost always (91-100%)

3: Impulse Control Difficulties (IMPULSE)

32) When I'm upset, I lose control over my behaviours
27) When I'm upset, I have difficulty controlling my behaviours
14) When I'm upset, I become out of control
19) When I'm upset, I feel out of control
3) I experience my emotions as overwhelming and out of control
24) When I'm upset, I feel like I can remain in control of my behaviours (R)

4: Lack of Emotional Awareness (AWARE)

6) I am attentive to my feelings (R)
2) I pay attention to how I feel (R)
10) When I'm upset, I acknowledge my emotions (R)
17) When I'm upset, I believe that my feelings are valid and important (R)
8) I care about what I am feeling (R)
34) When I'm upset, I take time to figure out what I'm really feeling (R)

5: Limited Access to Emotion Regulation Strategies (STRATEGIES)

16) When I'm upset, I believe that I'll end up feeling very depressed
15) When I'm upset, I believe that I will remain that way for a long time
31) When I'm upset, I believe that wallowing in it is all I can do
35) When I'm upset, it takes me a long time to feel better
28) When I'm upset, I believe that there is nothing I can do to make myself feel better
22) When I'm upset, I know that I can find a way to eventually feel better (R)
36) When I'm upset, my emotions feel overwhelming
30) When I'm upset, I start to feel very bad about myself

6: Lack of Emotional Clarity (CLARITY)

5) I have difficulty making sense out of my feelings
4) I have no idea how I am feeling
9) I am confused about how I feel
7) I know exactly how I am feeling (R)
1) I am clear about my feelings (R)

Appendix C

12-Item Short Form Health Survey (SF-12)

SF-12 Health Survey

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. **Answer each question by choosing just one answer**. If you are unsure how to answer a question, please give the best answer you can.

1. **In general, would you say your health is**:

□1 Excellent □2 Very good □3 Good □4 Fair □5 Poor

The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?

	YES, limited a lot	**YES, limited a little**	**NO, not limited at all**
2. **Moderate activities** such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	□1	□2	□3
3. Climbing **several** flights of stairs.	□1	□2	□3

During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u>?

	YES	**NO**
4. **Accomplished less** than you would like.	□1	□2
5. Were limited in the **kind** of work or other activities.	□1	□2

During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious)?

	YES	**NO**
6. **Accomplished less** than you would like.	□1	□2
7. Did work or activities **less carefully than usual**.	□1	□2

8. **During the <u>past 4 weeks</u>, how much <u>did pain interfere</u> with your normal work (including work outside the home and housework)?**

□1 Not at all □2 A little bit □3 Moderately □4 Quite a bit □5 Extremely

These questions are about how you have been feeling during the <u>past 4 weeks</u>.
For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the <u>past 4 weeks</u>…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9. Have you felt calm & peaceful?	□1	□2	□3	□4	□5	□6
10. Did you have a lot of energy?	□1	□2	□3	□4	□5	□6
11. Have you felt down-hearted and blue?	□1	□2	□3	□4	□5	□6

12. **During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting friends, relatives, etc.)?**

□1 All of the time □2 Most of the time □3 Some of the time □4 A little of the time □5 None of the time

Patient name: Date: PCS: MCS:

Visit type (circle one)
Preop 6 week 3 month 6 month 12 month 24 month Other:_____

Appendix D

Consent Form

Consent to Take Part in Research

TITLE: The role of premorbid psychological functioning in adjustment outcome for patients' with multiple sclerosis and Parkinson's disease.

INVESTIGATOR(S): Kellie L. Hadden, PhD, Michelle A. Hadden, MD, CCFP, Mark Stephanelli, MD, FRCPC, Kyna Squarey, MD, FRCPC, Allan Goodridge, Jackie Hesson, PhD You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time. This will not affect your usual health care. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study. Please read this carefully. Take as much time as you like. After you have read it, please ask questions about anything that is not clear by contacting the principal researcher, Dr. Kellie Hadden at: (709) 864-7675.

The researchers will: Discuss the study with you answer your questions, keep confidential any information which could identify you personally, be available during the study to deal with problems and answer questions.

Q117 Check here to indicate you have read the above information:

○ (1)

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1. Introduction/Background
Dealing with a chronic neurological disease can be very difficult and people adapt in different ways. Learning about the challenges that people with multiple sclerosis (MS) and other chronic conditions face in dealing with the symptoms of their illness can help us plan better treatment programs. It is, therefore, important for us to understand how you see the changes that have occurred since you first started to have symptoms of your illness. By understanding how peoples' past influences how they deal with their illness in the present, we can begin to separate what personality and emotional changes may be caused by your illness. We can also understand whether there are certain coping strategies and personality traits that help in adapting to chronic illness. To this end, we need your help in gaining a better understanding of your personality (past and present) and some of the ways you have tried to adapt to your chronic illness.

2. Purpose of the study
We have 3 main purposes for this study: To investigate how pre-existing personality traits relate to how people adapt to MS and PD. To investigate whether MS and PD patients' experience personality changes that are caused by the disease and how the patients' personality has changed. We are interested in understanding whether there are different stages of adapting to a chronic illness, or if adaption to the disease is specific to the type of chronic illness.

3. Description of the study procedures
We are interested in understanding whether people experience psychological changes as a result of having a chronic neurological disease. In particular, we are interested in whether you see changes in your

personality since your neurological symptoms started. We would also like to understand how you are adapting to your illness. If you agree to participate in this study we will ask you to complete several short questionnaires that ask questions about your personality, ways you cope, and your psychological wellbeing. One of the questionnaires focuses specifically on personality characteristics, which we will ask you to complete twice: (1) first telling us about your personality as you are today; (2) second telling us about your personality before your chronic condition (See Table). The time commitment in completing the study questionnaires is approximately one hour.

4. Length of time
Each of the questionnaires are short. We expect that the time to complete the questionnaires will take approximately one hour. You may pause and take breaks throughout completing the questionnaires, and you can come back to complete the questionnaires from where you left off for up to 7 days using the URL.

5. Possible risks and discomforts
The questionnaires are interesting to complete, but they may raise concerns about how you are feeling and coping. Dr. Hadden, a registered psychologist, will be available to talk to you if you have concerns. Taking time out of your day to complete the study questionnaires can be inconvenient.

6. Benefits
It is not known whether this study will benefit you.

7. Liability statement
Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

Q119 Check here to indicate you have read the above information:

○ (1)

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8. What about my privacy and confidentiality?
Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However, it cannot be guaranteed. For example, we may be required by law to allow access to research records. When you sign this consent form you give us permission to:
Collect information from you
Share information with the people conducting the study
Share information with the people responsible for protecting your safety
Use of your study information

The research team will collect and use only the information they need for this research study. This information will include your: age, sex, family history, medical conditions, medications, the results of tests and procedures you had before the study, information from study activities and questionnaires. Any identifying information will be kept secure by the research team in Newfoundland and Labrador. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study. Information collected for this study will be kept for ten years. If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study. Information collected and used by the research team will be stored (Department of Psychology, in Dr.

Hadden's office, in a locked filing cabinet). Dr. Kellie Hadden is the person responsible for keeping it secure.

9. Questions or problems
If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution.
That person is: Dr. Kellie Hadden at (709) 864-7675.

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through: Ethics Office Health Research Ethics Authority 709-777-6974 or by email at info@hrea.ca.

10. Declaration of financial interest, if applicable
There are no financial interests gained by the investigators of this study.

Q122 Check here to indicate you have read the above information:

○ (1)

Study Title: A 5-year investigation of the role of premorbid psychological functioning in adjustment outcome for patients' with multiple sclerosis and Parkinson's disease.
Name of principal investigator: Dr. Kellie Hadden.
Please complete the following:

Q122 I have read the consent.

○ Yes (1)

Q123 I have been given contact information, in order to ask questions or discuss the study as needed.

○ Yes (1)

Q124 I have received satisfactory answers to all of my questions.

- ○ Yes (1)

Q125 I have received enough information about the study.

- ○ Yes (1)

Q126 I understand that I am free to withdraw from this study at any time, without having to give a reason and without affecting my future care.

- ○ Yes (1)

Q127 I understand that it is my choice to be in the study and that I may not benefit.

- ○ Yes (1)

Q128 I understand how my privacy is protected and my records kept confidential.

- ○ Yes (1)

Q135 I agree to take part in this study.

- ○ Yes (1)
- ○ No (2)

Appendix E

Recruitment Poster

Are you interested in how physical health relates to mental health?

Researchers from the Departments of Psychology and Neurology, at Memorial University, are looking for healthy people to participate in a control group, which would involve completing an online survey. The survey includes questions associated with personality, mood, physical health, quality of life, and ways of coping with daily living. By participating in this study, you will be helping to understand how chronic illnesses, such as multiple sclerosis, affects emotional and psychological health.For more information contact Dr. Kellie Hadden at 864-7675 or khadden@mun.ca

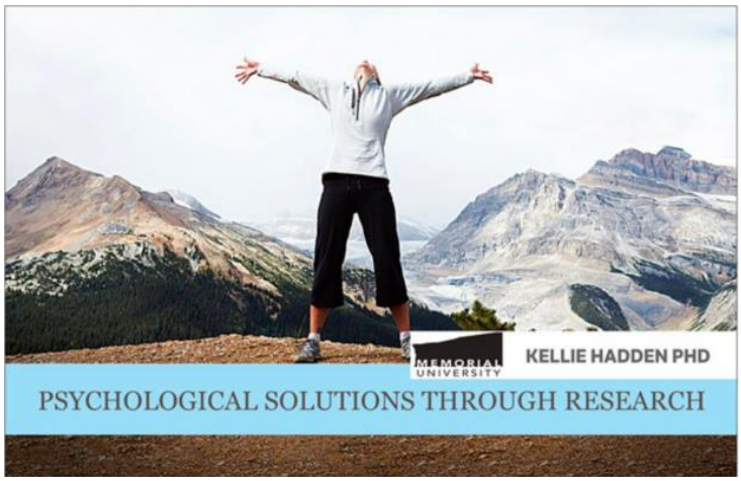
DEPARTMENT OF PSYCHOLOGY
MEMORIAL UNIVERSITY

SURVEY LINK:HTTPS://MUN.AZ1.QUALTRICS.COM/JFE/FORM/SV_9YSB8LOT3TJ0FXH

This study has been reviewed and received ethics approval by the provincial Health Research Ethics Board of Newfoundland and Labrador

Appendix F

Recruitment Card



DEPARTMENT OF PSYCHOLOGY
MEMORIAL UNIVERSITY
KELLIE HADDEN PHD

Psychological Solutions Through Research

I am an assistant professor in the Department of Psychology at Memorial University. I am engaged in several different research areas associated with pain, substance abuse outcomes in people experiencing their first psychotic episode, and the psychological impact of neurological diseases. I am currently working on a new research project with the Neurology Department at the Health Science Centre to identify different psychological factors that affect outcomes in multiple sclerosis (MS). We are currently looking for people with MS to complete an online survey that will help us understand the psychological factors that have the most significant impact on outcomes. We are also interested in people without significant health issues to complete the online survey to help narrow down specific psychological factors associated with MS outcomes. We hope that the information gained from this study can be used to develop interventions that will improve the lives of people with MS.

Online survey: https://mun.az1.qualtrics.com/jfe/form/SV_9ysb8lot3TJ0fxH

Phone: 709 864-7675
More Information: https://www.mun.ca/psychology/bio/hadden.php