Understanding Resilience in Persons with Multiple Sclerosis

by

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ABSTRACT

Background: Psychological resilience is a dynamic process of positive adaptation in the face of adversity or trauma. Multiple Sclerosis (MS), a chronic neurological disease, engenders adversity because of its progressive, uncertain and variable course. Resilience in persons with MS depends on the balance between their resources, such as a supportive social network, and their vulnerabilities, such as physical disability. Studies on resilience in those with MS demonstrate its association with better quality of life, social support and mental health. To better understand how resilience in those with MS might be strengthened it is important to identify factors associated with greater resilience and to understand how persons with MS experience resilience resources and vulnerabilities in their daily lives. ***Purpose:*** The aims of this body of work were to: 1) assess the degree of resilience amongst persons with MS and determine which sociodemographic, clinical and psychosocial factors are associated with greater resilience (study 1); 2) explore the factor structure and psychometric properties of a widely used measure of resilience, the Connor-Davidson Resilience Scale (CD-RISC), in persons with MS (study 2); and 3) explore how persons with MS describe their experiences of four components of resilience: adapting, coping, social support and wellness (study 3). ***Methods:*** Study 1 – Participants with MS completed a cross-sectional survey that included the CD-RISC and sociodemographic, clinical and psychosocial measures. The average resilience score was reported, and general linear models were built to determine the factors associated with greater resilience. Study 2 – Participants of Study 1 formed the study sample. Exploratory and confirmatory factor analyses were conducted on the CD-RISC, internal consistency was assessed using Cronbach's alpha, and construct validity was assessed through correlations among the CD-RISC score and sub-scales emerging from the factor analysis and health-related quality of life (Health Utilities Index Mark 3 (HUI3): multi-attribute and emotion subscales) and psychological well-being (Psychological Well-Being Checklist (PWB) subscales). Study 3 – For this qualitative study twelve participants were recruited from Study 1. Semi-structured interviews were conducted about four components of resilience: adapting to MS, coping with MS, social support and wellness. The interview data were analyzed using a qualitative description approach. ***Results:*** Study 1 – There were 358 surveys completed and returned. The average score on the CD-RISC was 72.4/100 (standard deviation 14.7). Nine factors were associated with greater resilience: older age, greater use of acceptance and cognitive/palliative (learning/faith) coping strategies, greater hope (goal setting and goal planning/execution), and better psychological well-being (autonomy, environmental mastery, personal growth and self-acceptance). Study 2 – Five factors emerged from the factor analysis of the CD-RISC: positive acceptance of change, personal competence, secure in oneself and others, perseverance, and spiritual influences. Internal consistency was 0.93 with 95% Confidence Intervals (CI) of 0.92-0.94. The CD-RISC scores showed correlations of 0.39-0.67 with the HUI3 and PWB subscales, and factors 1-4 showed correlations of 0.27-0.69 with the HUI3 and PWB. Factor 5, spiritual influences, was not significantly correlated with any of the HUI3 or PWB sub-scales. Study 3 – Participants described adapting to MS as changing their self-expectations, living differently, navigating roles and responsibilities, and adjusting to continually changing abilities. Coping with MS was described as acceptance, perspective, knowledge seeking, denial (when first diagnosed with MS) and faith. Social support was described as leaning on others, community and seeking expertise, but often involved strained connections and needing to maintain a distance from others. Wellness was described as managing symptoms and finding a path. ***Conclusions:***

The CD-RISC is a reliable measure of resilience in MS. Some of the factors associated with greater resilience are potentially modifiable, such as coping strategies. Longitudinal studies are needed to determine the temporal associations between these factors and resilience. Participants' mix of both positive and negative experiences in relation to adapting, coping, social support and wellness, highlights the importance of recognizing and acknowledging the difficulties or challenges that arise even in those aspects typically thought of as resources. This thesis work adds to our understanding of factors associated with resilience in MS, and how persons with MS describe their experiences of resilience. These findings can inform further research looking into the strengthening of resilience resources and lessening of resilience vulnerabilities, and the impact such changes may have on the health and well-being of persons with MS.

PREFACE

This thesis is an original work by Karen Vera Lyn Turpin. The research project, of which this thesis is a part, received ethics approval from the University of Alberta Research Ethics Board, Project Name "RESILENCE IN MULTIPLE SCLEROSIS, No. Pro00047262, AUGUST 19, 2014.

DEDICATION

For my family…

… my parents Ken and Jacquie Andersen, my sister Kirsten DeZutter, my husband Glen Turpin, and my sons Kyle and Joel Turpin.

“Families are the compass that guides us. They are the inspiration to reach great heights, and our comfort when we occasionally falter.” – Brad Henry

Thank you for staying beside me through the many ups and downs of this journey. I am forever grateful for your love and encouragement. You each supported me in your own unique ways, and I am truly blessed to be your daughter, sister, wife and mother. In the now infamous words of Joel, “I’m done”!

For my friend…

… Shauna Ankers. If there is a person who defines resilience, it is you. How you continue to care for others in spite of your pain is astounding. Thank you for your friendship, and for showing me how to put others first. You are a gem!

For the participants in my study…

… thank you for giving me your time, your insights, your answers. It was an honour and a privilege to work with the information you gave me so others may begin to understand what resilience may mean for persons living with MS. You do have strengths, you do have resources. You can counterbalance the hard things. Not perfectly, not every day, but over time, through growth in acceptance and hope.

“What lies behind us and what lies before us are tiny matters compared to what lies within us.” – Ralph Waldo Emerson

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I am incredibly grateful to my thesis committee for their dedication to this thesis work. They persevered through the many drafts I sent, always responding in a very timely manner with constructive feedback. This thesis is a compilation of our combined efforts to clearly and concisely add to the resilience in MS literature, helping to provide the springboard needed for resilience intervention studies aimed at enhancing the quality of life of those living with MS.

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Thank you for agreeing to be my supervisor once again. Your steadfastness through the years provided the stability I needed when I faced personal, education and research challenges. You walked me through each step of this PhD journey, and offered counsel on things both big and small. I could not have reached the finish line without you! Thank you for your commitment and care to this thesis work and to me as your student. I wish you every happiness in your retirement Linda.

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Marilyn Lenzen

The idea for this thesis work came from you. When I started by PhD, I thought I would do something on depression in MS, and I presented some ideas to you at an MS Society of Canada event. You made me aware how findings from studies on depression can be discouraging for persons with MS, and how important hope is for persons with MS. You graciously challenged me to think about "the flip side", about how we might address depression from another perspective. Hence, I started thinking of what the opposite of depression might be and discovered the concept of resilience. Depression is a difficult and common symptom or sequelae of MS, but perhaps this thesis work on resilience will help us to see how we might address it from the flip side and provide a sense of hope. Thank you for being at that MS Society event, and for entrusting me with your thoughts and ideas. I hope in some measure, this work encourages and strengthens you and other persons living with MS.

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I am indebted to the MS Society of Canada, and in particular, the endMS SPRINT program that I was a part of in 2012-13. The chance to attend two summer schools and participate in a MS project outside of my thesis was an incredible opportunity. I would like to thank Dr. Marcia Finlayson for being my endMS SPRINT mentor, and Dr. Christina Wolfson and her team for organizing the summer schools and SPRINT program. I made many connections with MS researchers, clinicians and graduate students, and developed an even greater appreciation for the breadth and depth of research that is being conducted to better the biopsychosocial outcomes of persons with MS.

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Study Participants

As mentioned in my dedication, thank you for participating. I know research often does not directly help those who participated, but rather helps persons in the future. Your contribution makes it possible to know how we might achieve more positive and healthier outcomes in the future. I hope you know how much that is valued. Thank you for sharing your thoughts and feelings with me, and for entrusting me with your information, so we can begin to understand what resilience may mean for persons with MS and begin to find ways to strengthen resilience. With much gratitude, Karen Turpin.

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LIST OF ABBREVIATIONS

ACT	Acceptance and Commitment Therapy
BIPS	Brief Inventory of Perceived Stress
CD-RISC	Connor-Davidson Resilience Scale
CD-RISC-25	Connor-Davidson Resilience Scale 25-Item
CD-RISC-10	Connor-Davidson Resilience Scale 10-item
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
CNS	Central Nervous System
CODI	Coping with a Disease Questionnaire
D-FIS	Daily Fatigue Impact Scale
EFA	Exploratory Factor Analysis
HADS	Hospital Anxiety and Depression Scale
HADS-A	Hospital Anxiety and Depression Scale – Anxiety Sub-scale
HADS-D	Hospital Anxiety and Depression Scale – Depression Sub-scale
HUI3	Health Utilities Index Mark 3
HRQL	Health-related Quality of Life
KMO	Kaiser-Meyer-Oklin Measure
PDDS	Patient Determined Disease Steps
PWB	Psychological Well-being
MD	Muscular Dystrophy
MCID	Minimal Clinically Important Difference
MS	Multiple Sclerosis
MSPSS	Multidimensional Scale of Perceived Social Support

NARCOMS	North American Research Committee on Multiple Sclerosis
NMSS	National Multiple Sclerosis Society (United States)
PPMS	Primary Progressive Multiple Sclerosis
PPS	Post-polio Syndrome
QOL	Quality of Life
QR	Quick Response Code
RCT	Randomized Controlled Trial
RMSEA	Root Mean Square Error of Approximation
RRMS	Relapsing-remitting Multiple Sclerosis
SCI	Spinal Cord Injury
SD	Standard Deviation
SPMS	Secondary Progressive Multiple Sclerosis
SRMR	Standardized Root Mean Square Residual
US	United States
VIF	Variance Inflation Factor

CHAPTER 1: Introduction

1.1. Overview of the Thesis

1.1.1. Background

The following thesis reflects quantitative and qualitative work done to understand resilience in persons living with multiple sclerosis (MS). MS is a chronic neurological disease, often punctuated by unpredictability, progression and variability between and within individuals[1]. Living with this disease can take a toll on all aspects of life. Persons with MS report many concerns including, but not limited to, physical limitations, difficulty maintaining employment and financial stresses, as well as psychosocial challenges, such as depression and social disconnection[2-4]. MS has been shown to have a detrimental impact on the physical and psychosocial health and well-being of persons living with MS[4-6]. Although current knowledge from research has been critical for highlighting the importance of addressing the physical and psychosocial difficulties of those with MS this often leads to a focus on what may be going poorly for a person[7]. An alternative approach is to study the more positive aspects experienced by persons living with MS, by focusing on facets and features of their lives that are going well[7]. Psychological resilience is one such positive aspect. Resilience has been defined as the process of adapting well in the face of adversity, trauma or significant sources of stress[8,9]. Thus, resilience, by definition, includes difficulties and distress, yet considers how persons may be able to thrive despite these hardships. The hallmark of resilience is in its recognition that persons can have both positive resources and negative vulnerabilities in their lives. Attention to resilience in MS research might provide a balanced approach to offset a focus on the negative. Finding ways to help persons with MS become more resilient, in addition to recognizing and addressing risk factors associated with more negative trajectories, may be one key to more positive and sustainable health and well-being outcomes.

1.1.2 *Purpose*

The purpose of this thesis was to begin the process of understanding resilience and its associated resources and vulnerabilities in those with MS. The goal in doing so is to provide information that will eventually support the development of evidence-informed initiatives that will strengthen resources and decrease the negative effect of vulnerabilities. The ultimate aim is to contribute to a body of research that enhances the lives of those living with MS. To that end, this thesis was designed to address three overall research questions:

1) What is the level of resilience amongst persons with MS? What sociodemographic, clinical and psychosocial factors are associated with greater resilience? (Study 1)
2) What are the underlying constructs contributing to resilience (i.e., the factor structure) of the commonly used measure of resilience, the Connor-Davidson Resilience Scale (CD-RISC), among persons with MS? (Study 2)
3) How do those living with MS describe their experiences of aspects of resilience resources and vulnerabilities? (Study 3)

1.1.3 Methods

This thesis used both quantitative and qualitative methods to address the research questions. A cross-sectional survey was developed and conducted to explore resilience and the sociodemographic, clinical and psychosocial factors associated with greater resilience in those with MS. Data from that cross-sectional survey were also used to explore the factor structure of the CD-RISC in those with MS. To provide a contextual understanding of the experience of resilience resources and vulnerabilities in the everyday lives of persons living with MS, a qualitative study was also conducted with a convenience sample of twelve participants.

1.2. Organization of the Thesis

This chapter (Chapter 1) provides a brief overview of MS and resilience. Chapter 2 provides a literature review on resilience in those with MS. Chapters 3, 4 and 5 report the three original studies that comprise this body of work. Chapter 6 provides an overall discussion that integrates the findings from the three original studies and discusses the potential significance of the results for persons with MS and the members of the MS health care community who work with persons with MS. Finally, Chapter 7 provides a brief synopsis of the thesis and future directions.

1.3. Overview of Multiple Sclerosis (MS)

MS is a chronic disease of the central nervous system (CNS), namely the brain, spinal cord and optic nerves. Due to inflammatory and neurodegenerative disease mechanisms, damage occurs causing disruption in the flow of the electric messaging from one neuron to the next[10]. Depending on where in the CNS the neurons are being attacked, the consequential disruption in the neuronal messaging system can elicit a wide variety of symptoms, given that the CNS controls all visual, sensory, motor, and autonomic functions. Symptoms can include visual impairments such as double vision or loss of vision; sensory disturbances including numbness, tingling and or pain; and motor difficulties such as loss of balance and or coordination and weakness[10]. Additional symptoms include bladder and bowel issues, cognitive dysfunction, fatigue, mood changes and sexual dysfunction[10]. The nature and severity of symptoms varies within and between individuals with MS. The majority of persons with MS, about 85%, have a disease trajectory characterized by periods of relapse and remission, termed relapsing-remitting MS (RRMS), whereby during times of relapse, the symptoms can be quite acute and pronounced, usually requiring medical intervention[11]. Times of remission tend to be characterized by an ability to manage symptoms. However, complete recovery from symptoms becomes increasingly difficult with repeated insults to the CNS. Over time, persons with this initial type tend to convert to a disease trajectory characterized more by a progressive decline in function, although relapses can still occur. This change in disease path is known as secondary progressive MS (SPMS). Some individuals, about 5-15%, experience progressive decline from the outset of their diagnosis, referred to as primary progressive MS (PPMS)[11].

Based on an estimated prevalence of 290 cases of persons with MS per 100,000 population, the highest prevalence in the world, about 100,000 Canadians are currently living with MS[12]. High prevalence tends to be found in countries with colder climates like Canada and Scandinavian countries (e.g.; Denmark 227/100,000), United Kingdom (164/100,000), Germany (149/100,000) and the northern United States (above the 37th parallel) (110-140/100,000)[13]. The ratio of women to men having MS has increased over the past century with women generally two to three times more likely to have MS[14]. Currently, there are about 2.6 women to every 1.0 men in Canada living with MS[12]. Most persons are diagnosed between the ages of 20 and 50 years[12]. The gap between symptom onset and diagnosis tends to depend on age with younger persons experiencing a much wider gap than older persons. The 2011 Survey of Living with Neurological Conditions in Canada found that persons who are diagnosed with MS between the ages of 15 and

19 reported that they first noticed symptoms about 10.5 years before they were diagnosed with MS. The gap between symptom onset and diagnosis was less for those persons diagnosed between the ages of 20-29 (average gap of 4.3 years), 30-39 (4.5 years), 40-49 (2.6 years), and only 2.0 years for persons older than 50 years of age[12].

As persons with MS tend to be diagnosed in young adulthood, most often around age 30, many are going to be living with this chronic disease for 40+ years[15]. Although the cause of MS remains elusive and there is no cure, strides have been made in regards to MS care, including treatments for modifying the disease[16]. Advances have also been made in our understanding of the pathophysiology of the disease[10]. Despite these developments in treatments and understanding of the disease, for persons living with MS, the past – how they "got" MS and the future – how the disease will affect them, are largely mysteries. While epidemiologic and clinical studies have provided insights into potential etiologic factors, clinical characteristics and disease trajectories, our ability to tell persons with MS why they developed MS or what their long-term disability prognosis might be, remains limited. The uncertainty that accompanies a diagnosis of MS places immense emotional strain on those living with MS, and often results in poor adjustment, ineffective coping and decreased quality of life[17-20]. As the number of Canadians living with MS continues to grow yearly[15], it is imperative that MS researchers and clinicians find ways to help those living with the disease optimize their ability to live well with this chronic progressive disease. Research regarding resilience in MS may help achieve this goal.

1.4. Overview of Resilience

The concept of resilience is emerging in clinical circles and research literature as a productive way to view the outcomes and experiences of living with a chronic disease such as MS and its associated stressors[8,9]. However, there is variability in the definition of resilience used in studies of physical disease resilience[21]. The origins of resilience research are in the developmental psychology domain, as researchers were interested in why some children appeared to persevere and thrive despite trauma, abuse or war and others fared less well[22]. Initially, that research tended to focus on the enduring traits, protective factors or resources that made some children more resilient than others[22]. As resilience research spread into other arenas of adversity, such as chronic disease, the definition of resilience also expanded and changed. This was in acknowledgement of the fact that the study of “resilience traits” did not clarify how individuals access or use resources to overcome adversity, how the environment interacts with individual characteristics to increase or decrease resilience, or how life course trajectories affect resilience[22]. A 2011 narrative review of resilience definitions reported that while there may be a lack of consensus regarding an operational definition of resilience, resilience is often defined using similar domains[23]. The review also identified two key concepts of resilience for use in clinical work: the dynamic nature of resilience throughout the life span and the interaction of resilience in different ways with major domains of life function (physical, mental, social and environmental). In a more recent systematic review of resilience definitions and study methods in physical disease and resilience outcomes, the authors found that consensus is building to consider resilience as a dynamic process that varies across the life course and across different domains rather than a fixed personality trait[24]. Viewing resilience as a dynamic process across the lifespan rather than a trait is important when studying resilience in those with chronic diseases such as MS, as persons with MS will be living and aging with the disease, potentially over many years. Further, defining resilience as a process inherently allows for persons to develop and strengthen resilience.

Within the context of chronic disease, resilience has been defined as the adaptive response to adversity and has three key components of adaptive outcomes: recovery, sustainability and growth[8,9]. Recovery can be thought of as how well people bounce back emotionally from stressful events, sustainability as how well people maintain a sense of purpose and meaning within the context of a chronically changing and stress-ridden life, and growth as how well people are able to gain new insights and enhance their capacity for overcoming difficult and ongoing stressors[8,9]. This three-component framework of resilience contrasts with traditional deficit models of chronic disease and stress that primarily emphasize amelioration of risk factors and negative outcomes. The resilience framework provides a balanced perspective by explicitly accounting for personal and environmental resources in addition to risks and vulnerabilities[8,9].

Briefly, the two important aspects of resilience are resources and vulnerabilities, both of which include personal and environmental facets[8,9]. Resources are a composite of assets such as effective coping skills, a sense of purpose in life, and emotional and practical support from external sources[25]. Vulnerabilities are a composite of factors such as poor health, anxiety, depression and lack of a support network[25]. Viewing MS from this perspective involves giving explicit consideration to the differential effects these resources and vulnerabilities have on the ability of those living with MS to respond adaptively to their disease and its consequences.

Thus, the resources and vulnerabilities that comprise resilience can be thought of as being the two sides of a balance scale. To understand how to improve the health and well-being of persons with MS, we need to understand not only the general and MS-specific vulnerabilities, but also what personal and environmental resources are the most critical in counterbalancing those vulnerabilities.

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CHAPTER 2: Literature Review of Resilience Research in Multiple Sclerosis

2.1. Introduction

Research on resilience in persons with MS began to emerge in the early 2000s, with most of those studies having been published in the past four years. A 2005 critical review of the nature and scope of depression in persons with MS suggested that factors enhancing emotional resilience need to be explored, especially given the fact that many individuals not only persevere but thrive in spite of adversity, trauma, tragedy, loss or serious medical illness[1]. The authors found little empirical information on positive responses to living with MS, such as resilience, positive emotions and post-traumatic growth, either during or after the diagnosis of MS.

The majority of studies on resilience in those with MS are quantitative, and most employ a cross-sectional design, examining associations between potential resilience resources and vulnerabilities with resilience. Two pilot intervention studies have also been conducted to explore the impact of resilience-based interventions on the health and well-being outcomes of persons with MS[2, 3]. The studies conducted to date on resilience in MS have used a variety of instruments to measure resilience, with the most common being the Connor-Davidson Resilience Scale (CD-RISC). The CD-RISC is widely used to measure resilience in other populations and is a validated generic measure of resilience[4]. Although resilience research in MS is growing, gaps remain in our knowledge of factors that may contribute to greater resilience and of ways persons with MS experience resilience in their daily lives. A review of studies on resilience and MS follows. First, MS-specific quantitative studies reporting predictors or correlates of resilience are reported. Next, studies reporting predictors or correlates of resilience which included, but were not limited to, those with MS are reported. These are listed separately from the first group of studies, since it cannot be determined if the findings are necessarily relevant to those with MS, as findings might have been driven by other groups in the study sample. Finally, qualitative studies on resilience and MS are reported. After the review of resilience and MS, the resilience measures that have been used in those with MS are outlined. Following that are a summary and statement of the research questions.

2.2. Resilience and MS: MS-specific Studies

2.2.1. Intervention Studies

This section reports on two randomized controlled trials (RCTs) in which resilience was included as a secondary outcome, but where the intervention was not designed to specifically address resilience, and two studies (one of which was an RCT) utilizing an intervention specifically designed to improve resilience. Findings from all these studies are difficult to interpret without information about what change in resilience scores is clinically important.

First, one study was designed to evaluate the efficacy of a telephone-delivered self-management program aimed at addressing fatigue, pain and depression in adults with MS[5]. Participants had to have at least one of depression, fatigue or pain at the outset, and baseline self-report measures were repeated at weeks 10, 26 and 52. The intervention resulted in statistically significant improvements in resilience; however the differences in pre- and post-intervention scores were small and of unclear clinical significance[5].

A second was a small pilot study of an eight-week cognitive behavioral intervention whose aim was to treat depressive symptoms in those newly diagnosed with MS[6]. There was an improvement in resilience in the intervention group, compared with the group receiving "usual care" which did not address the depressive symptoms. That improvement was retained up to 20-weeks post-treatment. However, there were pre-intervention differences between the groups, including a higher percentage of participants taking anti-depressants and MS disease modifying medications in the intervention group. Thus, it is difficult to be certain that the cognitive behavioral intervention was responsible for the change in resilience[6].

The first of the resilience-specific intervention studies involved a pilot study (pre-post design with no comparison group). It aimed to evaluate the feasibility of an Acceptance and Commitment Therapy (ACT) based resilience-training program for people with MS and found improvements in resilience, physical and mental quality of life (QOL), depression and stress[2]. The ACT program included teaching and learning activities about: (1) physical activity, (2) mindfulness (staying focused on the present), (3) cognitive defusion (seeing thoughts as just thoughts and feelings as just feelings, rather than seeing thoughts and feelings as how things really are and the determinants of what to do), (4) self-as context (thoughts and feelings will come and go, but real self does not change), (5) acceptance, (6) values and meaningful action (discover and commit to actions that focus on the things one cares about), (7) social connectedness, and (8) pleasant activities. Of these eight facets, cognitive defusion, acceptance and values and meaningful action demonstrated significant improvements from pre-intervention to post-intervention. The authors suggested these three factors may be protective factors of resilience in persons with MS. However, without a comparison group, it is difficult to reach firm conclusions about the effectiveness of the resilience intervention.

Another pilot study (RCT) evaluated the feasibility and preliminary effects of a positive psychology intervention on resilience in adults aged 45 or older living with MS[3]. The resilience intervention tested in that study was a program developed by the National MS Society to improve resilience by providing persons with MS with knowledge and skill development on goal setting, happiness habits, retraining cognitions for positivity, building social connections, removing barriers to action, and gaining positive momentum. In that study, the treatment group had a greater increase in resilience than the waitlist comparison group[3].

2.2.2. Cohort Studies

There is one study in this category. Data from the first RCT mentioned above were used to conduct a subsequent cohort study investigating the relationships between social support and subsequent mental health outcomes and to examine resilience as a mediator between social support and subsequent mental health outcomes[7]. At all four time points of the study (baseline and weeks 10, 26 and 52), social support was significantly associated with less depressive and anxious symptoms and better general mental health status. Resilience mediated the relationships between social support and the mental health outcomes. When resilience was controlled for, nearly all the relationships between social support (significant other, family and friends) and mental health outcomes were no longer significant. Support from significant others was no longer associated with depressive or anxious symptoms, support from family no longer associated with general mental health, and support from friends no longer associated with anxious symptoms or general mental health. This suggests that resilience is an important pathway through which social support impacts health[7].

2.2.3. Cross-sectional Studies

One study conducted to propose and test a model of resilience in those with MS incorporated biological, psychological and social variables and found greater resilience was positively associated with positive affect (positive emotions and expressions) and self-efficacy (perceived ability to overcome the challenges associated with MS) and negatively associated with negative affect (negative emotions and expressions)[8]. Higher levels of fatigue and lower physical independence (amount of assistance a person requires for everyday living) were negatively associated with resilience, though indirectly through negative affect and lower self-efficacy. Social support frequency and satisfaction was positively associated with resilience, though also indirectly through positive affect and higher self-efficacy. Of the two social support sub-scales, satisfaction with social support had a stronger relationship with affect and self-efficacy, and thereby resilience, than frequency of social support. The authors suggested that quality of social support may be a more important aspect of resilience than quantity[8].

In another study that investigated the role of resilience in the relationship between affective disorders, including depression and health-related quality of life (HRQL) in adolescents and young adults with MS (ages 14-23), resilience was explored as both a personality trait and as a competence (process through which people can acquire and improve ability to face adversity)[9]. “Trait” resilience was negatively associated with HRQL, whereas “resilience competencies of individual resources” (personal skills, peer support, social skills) and relational resources (having physical and psychological caregivers) were positively associated with HRQL. Further, resilience competence was found to moderate the relationship between depression and the emotional function sub-scale of HRQL[9]. The results of this study support the idea that resilience is a dynamic process rather than a trait that persons with MS either do or do not have[10, 11].

In a study that explored the inter-relationships among resilience, positive affect (positive emotions and expressions), pain intensity and function (pain interference, depressive symptoms), resilience was found to mediate the associations between positive affect and pain function[12]. The authors thus suggested positive affect was indirectly related to pain interference and depression through resilience, citing positive affect as a potential builder or resource of resilience. In a similar study exploring the relationships between positive affect, negative affect, depression, fatigue, pain and resilience, greater resilience was found to be associated with less severe pain and fatigue through positive affect[13].

A study exploring the relationship between mindfulness and perceived stress, coping and resilience in people with MS found mindfulness, understood here as paying attention to one's thoughts and feelings without over identifying them and without responding to them in an automatic or habitual way, was associated with greater resilience[14]. Further, mindfulness accounted for 44% of the variance in resilience after adjusting for age, gender, education, disability status, use of disease-modifying therapy, and type of MS. A study looking at the relationships among self-compassion (desire to ease one's own suffering through offering self-kindness and nonjudgmental understanding), HRQL and resilience found self-compassion had both a direct effect on HRQL and an indirect effect on HRQL through resilience[15]. Self-compassion and resilience explained 51% of the variance in HRQL, and self-compassion explained 40% of the variance in resilience[15].

With regard to the association between sex and resilience, a large study of older (55 years and older) adults with MS found men to have lower mean resilience scores than women after adjusting for age, years with MS, disability, fatigue and social support[16]. However, the men in that study were more likely to have progressive MS, depressive symptoms, poorer diet habits, less participation in household activities and out-of-home activities, and poor perceived health, which might explain those findings. In contrast, another study found no differences between overall resilience scores of men and women, although higher scores were found in those who were older, had more education and longer disease duration[17]. However, in that same study, two resilience subscales, support from family and friends and spirituality, showed higher scores for women.

2.3. Resilience in Physically Disabled Populations (Including MS)

2.3.1. Cohort Studies

A large sample of adults aging with MS, muscular dystrophy (MD), post-polio syndrome (PPS), or spinal cord injury (SCI) formed the basis of two cohort studies (reported here) and two cross-sectional studies (reported in the next section). Those studies focused on resilience and its association with pain, fatigue, depression and QOL. In the first of these cohort studies, a decrease in resilience over a one-year period was associated with an increase in depression and fatigue, while an increase in resilience was associated with improved sleep quality and physical function (after adjusting for age, sex and diagnosis)[18]. The second cohort study from that dataset investigated the longitudinal relationship between resilience and four health domains (anxiety, depression, physical function and social role satisfaction) over a two-year time period[19]. There were reciprocal relationships between resilience and each of anxiety, depression and satisfactions with social roles but not with physical function. The authors suggested that resilience and non-physical function influenced each other simultaneously over time (e.g., greater resilience led to greater satisfaction with social roles, and greater satisfaction with social roles led to greater resilience) and that resilience may have only minimal relevance to improved physical functioning[19].

2.3.2. Cross-sectional Studies

In one cross-sectional analysis of the above study, participants with MS or MD had lower resilience scores, as measured by the CD-RISC 10-item scale, than the SCI and PPS participants. Older individuals (65 years of age or older) had higher scores than those under the age of 65[20]. However, despite these differences in scores being statistically significant, they were very small (1-2 points on the 50-point scale) and of unclear clinical significance. Resilience did not vary by sex. Pain, fatigue and depression were negatively associated with resilience. Resilience was found to mediate the effects of pain and fatigue on depression and QOL[20]. In the second cross-sectional analysis of those data, sex was found to moderate the association between resilience and satisfaction with social roles, with resilience accounting for more of the variance in satisfaction with social roles in men than women.

In a study that included those with MS, SCI, amputation and chronic pain, resilience resources and resilience vulnerabilities were examined to determine their independent contributions to pain interference, self-efficacy for managing pain, and global mental and physical health[21]. Positive affect was classified as a resilience resource, along with pain acceptance and two adaptive pain beliefs (pain control and pain emotion). Depressive symptoms, pain catastrophizing and two maladaptive pain beliefs (pain disability and pain solicitousness) were considered resilience vulnerabilities. The results indicated that both the resources and the vulnerabilities contributed to pain interference and global physical health, but neither set was able to make a substantial contribution above and beyond the other. However, for self-efficacy and global mental health, results indicated the resources did make a meaningful contribution above and beyond the vulnerability factors, suggesting the important contribution of resources to the psychological experience of pain.

The relationships among resilience, psychiatric symptoms and QOL were examined in Japanese patients with MS or neuromyelitis optica spectrum disorder[22]. Resilience was negatively correlated with depression and anxiety and positively correlated with QOL.

2.3.3. Systematic Review

A 2011 systematic review of 52 studies on resilience conducted in physically ill patients included one study focused on MS and three studies whose samples included those with MS along with other diseases, and the remaining 48 studies focused on those with cancer, HIV/AIDS, diabetes, cardiovascular disease, arthritis and other medical conditions. In that mixed group of studies of physically ill patients, the following factors were associated with resilience: self-efficacy, self-esteem, internal locus of control, optimism, mastery, hardiness, hope, self-empowerment, acceptance, determination, personal growth and social support[23]. Coping strategies such as positive cognitive appraisal, spirituality and active coping were also associated with resilience. The authors stated that many of these factors are also associated with, or predictive of, resilience in those with non-health related forms of adversity. However, the authors also pointed to additional factors specific to physical illness, including self-care, adherence to treatment recommendations, health-related quality of life, illness perception, pain perception, exercise adherence and physical outcomes[23].

2.4. Qualitative Studies on Resilience in MS

In a qualitative study conducted with persons with MS and their partners and community stakeholders, participants identified five major supports to resilience: psychological adaptation, social connection, life meaning, planning and physical wellness[24]. In that study, "psychological adaptation" included coping, humour, optimism, flexibility, "new normal", perseverance, acceptance and self-compassion. "Social connection" included connecting with family, friends and peers with MS. "Life meaning" included family relationships and engaging undertaking hobbies and volunteerism. "Planning" included attention to logistics, routines, not overcommitting one-self and simplifying life. "Physical wellness" included exercise, stress reduction and energy management. The participants also identified the following barriers to resilience: resilience depletion (feeling burned out), negative thoughts and feelings (depression/sadness, giving up, low self-worth, anger, dwelling on what one cannot do), social barriers (wearing out or losing friends, people not understanding MS), stigma (denial, refusing accommodations, concealing MS from others) and physical fatigue (exhaustion, missed social opportunities)[24].

Another qualitative study with persons with MS aimed to explore what persons aged 55 and older viewed as important for healthy aging[25]. The authors concluded that resilience, mental/cognitive health, financial flexibility and social support facilitated work and social engagement, effective and accessible health care, healthy lifestyle habits and maintaining independence at home, which the participants indicated were critical aspects of healthy aging. Participants in this study described resilience as encompassing an ability to adapt to change and to disease symptoms, to seek out and gain new knowledge, to pursue self-therapy, to deal with uncertainty, to resolve problems on one's own, and to cope with and overcome barriers[25].

Likewise, the idea that resilience is an important facet in healthy aging was also supported in another qualitative study designed to examine perspectives of successful aging in adults aged 49 years or older with MS, MD, SCI or PPS[26]. The participants in that study described resilience as emotional mastery and the avoidance of negative chronic mood states, psychological resilience and the ability to adapt to new circumstances. Other facets identified by participants as important to heathy aging included autonomy, social connectedness and physical health (including access to general and specialty health care)[26].

2.5. Measures of Resilience Used in MS

The Connor-Davidson Resilience Scale (CD-RISC), the measure of resilience used in this thesis, is a widely used validated measure of resilience[4]. There have been some initial efforts to demonstrate responsiveness, although those works were preliminary and, like other measures of resilience, no minimal clinically important differences were identified[27]. The CD-RISC contains 25 items that explore ability to adapt to change; deal with what comes along; cope with stress; stay focused and think clearly; not get discouraged in the face of failure; and handle unpleasant feelings such as anger, pain and sadness[4]. Initial validation work on the CD-RISC found that the questionnaire had a five-factor model labelled by the test developers as: personal competence, acceptance of change and secure relationships, trust / tolerance / strengthening effects of stress, control and spiritual influences[28]. However, the factor structure appears to vary depending on what population is being studied[28].

The CD-RISC has been used to measure resilience in a variety of populations including general populations, students and young adults, those with post-traumatic stress disorder and persons exposed to severe trauma, those with depression and other psychiatric disorders, and in groups with medical problems, including MS[4,14,28]. A shortened, validated version of the CD-RISC was developed containing 10 questions from the original 25. The shortened version, the CD-RISC-10, has also been used to measure resilience in those with a variety of chronic diseases, also including MS[3,5,7,8,12,13,15,20]. There is also a 2-item version that is seldom used[28]. The wide use of the CD-RISC in various clinical and non-clinical studies theoretically allows for comparisons to be made among these various populations under study, though the authors stress that scores vary by location / region where the data are collected and nature of the sample[28]. The CD-RISC has been used to measure resilience in a variety of countries. However, to the best of this author's knowledge, it has not been used previously to measure resilience in Canadians with MS.

Other resilience scales used in studies of those with MS include the 15-item Resilience Scale[29], the 25-item Resilience Scale[30], the Resiliency Scale[31], the Ego-Resiliency Scale (resilience as a personality trait)[32], the Child and Youth Resilience Measures-28[33], the Brief Resilience Scale[34], the Resilience Scale for Adults[35], the Dispositional Resilience Scale[36] and the recently developed MS Resilience Scale[17]. In a review of the available resilience scales, the CD-RISC[4], along with the Resilience Scale for Adults[35] and Brief Resilience Scale[34] were identified as having the best psychometric properties[27].

2.6. Summary and Research Questions

The study of resilience in those with MS began only a decade ago and studies are still relatively sparse. There is initial evidence (primarily from pilot studies) that resilience in those with MS can be improved with intervention, although this evidence requires larger, fully powered studies, and findings would be clearer if we knew what improvement in resilience scores is clinically important[2,3,5,6]. There is also evidence from one MS-specific cohort study that resilience mediates the relationship between social support and subsequent mental health[7]. Using quantitative and qualitative methods, the available MS-specific studies on resilience have variously identified a number of resilience resources, including social support, positive affect, self-efficacy, health, adaptation and coping[2,3,8,9,24-26]; along with a number of vulnerabilities such as depression, fatigue, pain and stress[5,9,13,14]. In non-MS-specific studies, hope and psychological well-being have also been found to be associated with resilience[23].

There has been little overlap in which resources and vulnerabilities are studied in MS-specific resilience studies. Although adaptation and coping have been identified in qualitative studies of persons with MS as resilience resources, they have not been tested in quantitative research. Hope and psychological well-being have been found to be associated with resilience in mixed samples with physical disabilities but not in MS-specific samples. Furthermore, the level of resilience in Canadians with MS has not been studied. This has given rise to the first two research questions addressed in this thesis: (1) *What is the level of resilience amongst persons with MS?* and (2) *What sociodemographic, clinical and psychosocial factors are associated with greater resilience?* These questions were answered using a cross-sectional survey of adults with MS (Study 1).

There also has been little attention paid to the MS-specific psychometric properties of the resilience scales used, such as the factor structure of the widely used CD-RISC scale. Thus, given that the factor structure appears to vary by population studied, the third research question addressed in this thesis was: *What are the underlying constructs contributing to resilience (i.e., the factor structure) of the commonly used measure of resilience, the Connor-Davidson Resilience Scale (CD-RISC), among persons with MS?* Data from the cross-sectional survey were used to address this question (Study 2).

Lastly, there has been no exploration of how persons describe their experiences of resilience resources and vulnerabilities. Since this information will help us start to understand how to help those with MS maximize these resources and minimize the impact of the vulnerabilities, the third study used qualitative methodology to address the fourth research question: *How do those living with MS describe their experiences of aspects of resilience resources and vulnerabilities?* (Study 3). Other gaps in the literature are addressed in the final two chapters of this thesis (Discussion and Future Directions).

It is anticipated that this thesis work will contribute to the growing literature on resilience resources and vulnerabilities in persons with MS. By using both quantitative and qualitative methodologies, an understanding of the associations among the factors of interest can be obtained, as well as an understanding of how persons with MS describe their experiences with these factors in daily life. As research is beginning to turn to the feasibility and usefulness of resilience-based interventions on the health and well-being outcomes of persons with MS, these findings will contribute to our knowledge and understanding of what factors may strengthen or weaken resilience.

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CHAPTER 3

Manuscript Title: Factors associated with resilience in persons with multiple sclerosis

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CHAPTER 3: Factors Associated with Resilience in Persons with Multiple Sclerosis (Study 1)

3.1. Chapter Synopsis

Background: Psychological resilience is the ability to adaptively respond to adversity. A key source of adversity for persons with multiple sclerosis (MS) is the unpredictable, variable and progressive nature of the disease. The degree of resilience demonstrated by persons with MS depends on the strength of their resources, such as self-acceptance and effective coping skills, to counterbalance their vulnerabilities, such as depression and stress. Resilience research in MS is needed to promote the health and well-being of persons with MS. The few studies that have been conducted to date exploring the potential impact of resilience on health and well-being outcomes of persons with MS have demonstrated its association with better quality of life, social support and mental health. To better understand how resilience might be strengthened to foster and sustain favourable outcomes, it is important to identify factors associated with greater resilience. Interventions based on creating and enhancing these resources can then be built, in order for the resilience-based interventions to have the greatest potential impact on health and well-being outcomes. ***Purpose:*** The aim of this cross-sectional study was to assess the degree of resilience amongst persons with MS and to determine which sociodemographic, clinical and psychosocial factors are associated with greater resilience. ***Methods:*** Participants were recruited from four western Canadian MS Clinics and through the MS Society of Canada's newsletters. Data collection was through an online questionnaire, including a validated, reliable measure of resilience, the Connor-Davidson Resilience Scale (CD-RISC) and measures assessing sociodemographic, clinical and psychosocial factors. General linear models were built for determining the factors associated with greater resilience. ***Results:*** Most respondents (N=358)

were female (79.2%). The participants’ average age was 48.2 (SD=11.7, range 21-77). The participants’ average score on the CD-RISC was 72.4/100 (SD=14.7, range 23-100). Nine factors were associated with greater resilience: (1) older age; greater use of (2) acceptance and (3) cognitive/palliative (learning/faith) coping strategies; higher use of (4) hope agency (goal setting) and (5) pathway (goal planning/execution) strategies; and higher scores on psychological well-being (6) autonomy, (7) environmental mastery, (8) personal growth and (9) self-acceptance sub-scales. Together these factors explained 76.1% of the variance in the CD-RISC scores. ***Conclusions:*** The resilience score of 72.4 is lower than general population scores but similar to scores reported in comparable studies measuring resilience in MS and higher than scores reported for those with other health conditions such as chronic back pain and psychiatric conditions. Coping, hope (goal setting and planning) and psychological well-being are potentially modifiable. Longitudinal studies are needed to determine if changes in these factors lead to changes in resilience.

3.2. Introduction

MS is a chronic, often progressive, disease that causes a number of physical and psychosocial challenges for persons with MS throughout their disease course[1,2]. Disability tends to worsen over time for the majority of persons with MS, though treatments aimed at directly modifying the disease have slowed down this trajectory[3]. However, disability progression is impacted by factors other than the pathophysiology of MS. Physical comorbidities such as heart disease and psychiatric comorbidities such as depression are quite common among persons with MS and contribute to disability progression[4,5]. Beyond physical disability and comorbidities, symptoms of fatigue, urinary incontinence and cognitive dysfunction are also common and directly impact the quality of life of persons with MS[6,7]. The stress that often accompanies dealing with the complexities and consequences of MS symptoms, including navigating personal goals, family roles and responsibilities, employment situations, and health care and government systems, can be difficult to endure[8-10].

Traditionally research has centered on identifying risk factors associated with poorer outcomes and testing interventions designed to address those risk factors. While it is important to target these negatives, doing so often leads to overlooking those aspects that are going well in the lives of persons with MS[11]. Strategies that acknowledge the positive aspects in addition to the negative impacts could aid in lessening the impact of negative emotions and stressors[11]. Resilience, the process of adapting well to adversity, trauma, tragedy, loss or chronic illnesses such as MS, provides a framework for exploring how positive aspects might be enhanced and negative aspects lessened, thus contributing to improved outcomes[12-15]. The opportunity that the resilience framework brings to the study of the health and well-being of persons with MS is furthered by its inclusion of three adaptive outcomes: recovery, sustainability and growth. Recovery can be thought of as how well people bounce back emotionally from stressful events; sustainability as how well people maintain a sense of purpose and meaning within the context of a chronically changing and stress-ridden life; and growth as how well people are able to gain new insights and enhance their capacity for overcoming difficult and ongoing stressors[12]. This definition of resilience provides scope for persons to learn and develop their resources to face future challenges with enhanced capacities.

Resilience provides a balanced perspective regarding the lives of persons with MS, because it promotes an appreciation of both vulnerabilities and resources. Vulnerabilities can include factors such as physical and psychological symptoms and limitations as well as social aspects such as employment difficulties and lack of a support network[16-19]. Resources can arise from a sense of purpose in life, problem-focused coping skills and emotional and practical support from family and health care providers[17-20]. The vulnerabilities and resources of an individual with MS can be thought of as the two sides of a balance scale (Figure 3.1). To understand how to strengthen resilience in persons with MS, we need to understand general and MS-specific vulnerabilities and what personal and environmental resources are the most effective at counterbalancing those vulnerabilities.

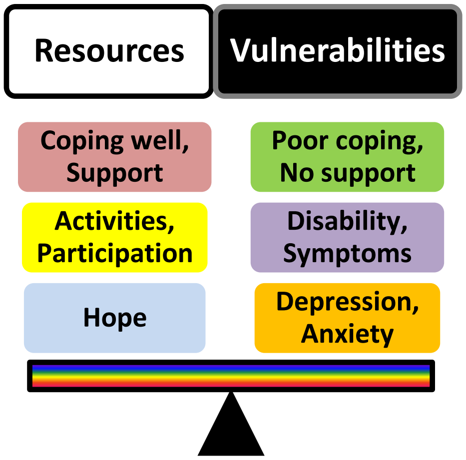

Figure 3.1. Resilience Framework

Resilience research in MS is beginning to emerge and may point the way to new interventions for improving and maintaining health and well-being outcomes. Better perceived health-related quality of life, social support and mental health were reported in studies exploring the impact of resilience[18,21]. To continue adding to our understanding of resilience in the MS population, and with the eventual goal of developing interventions that have the most potential to impact outcomes, we need to identify and understand what factors are associated with resilience, how these factors affect resilience and how to evaluate the role resilience plays in the well-being of those with MS. Thus, the aim of this cross-sectional study was to assess resilience amongst persons with MS and, as a first step in understanding resilience in this population, to determine which sociodemographic, clinical and psychosocial factors are concurrently associated with greater resilience.

3.3. Methods

3.3.1. Participants, Data Collection Methods and Sample Size Calculations

Participants with MS were recruited to complete a self-report survey titled "The Resilience in MS Questionnaire" (Appendix E), a compilation of validated questionnaires regarding resilience, sociodemographic, clinical and psychosocial factors (measures described in the next section). The participants were recruited from four MS specialty clinics in Western Canada and through the MS Society of Canada's print and e-newsletters from March 2015 to April 2016. Posters were placed in the three MS clinics in Alberta, where potential participants also received a brief informative handout as they registered with the clinic receptionists for regularly scheduled appointments. These posters and handouts contained a web address and quick response (QR) scan code for completing the anonymous survey online. Paper and pencil versions were also available with the clinic receptionists for immediate distribution along with postage-paid self-return envelopes. Recruitment from the fourth site, located in Manitoba, was done by mailing study information to 150 potentially eligible participants who had previously consented to being contacted about research studies.

Ethics approval was obtained from the University of Alberta and University of Manitoba's Health Research Ethics Boards (Appendices A and B). Inclusion criteria were: (1) age ≥18 years, (2) English-speaking, (3) self-reported confirmed diagnosis of MS by an MS specialist, (4) self-reported confirmation of having MS for at least two years since symptom onset, and (5) ability to complete the questionnaire independently. The rationale for including only those who had MS for at least two years was that the first couple of years can be a difficult time of adjustment[10, 22], and therefore, those newly diagnosed may have different factors associated with resilience.

Eligibility criteria were specified in the recruitment posters, information handouts, newsletters, and introductory page of the questionnaire. Because the surveys were completed and returned anonymously, adherence to inclusion criteria was ascertained solely through self-report. The surveys were anonymous to reduce the possibility of response bias.

The University of Alberta Evaluation and Research Services managed the online version, allowing data to be collected using the secure servers of the University of Alberta. The data were sent to the researchers via secure encryption methods in the form of an EXCEL spreadsheet. The paper-based questionnaires were returned anonymously by the participants via pre-paid postage return envelopes. These data were manually entered in an EXCEL spreadsheet containing the online data.

Assuming beta = 0.20 and alpha = 0.05 and the dependent variable of resilience would meet the linearity, normality and independence assumptions of a multivariable linear regression, the estimated sample size required was 280. Ten to fifteen independent variables were expected to compose the final model and collectively expected to explain >50% of the variance in resilience. A sample size of 280 would ensure adequate estimation of the regression coefficients, standard errors, confidence intervals, and adjusted r-square values with >10 participants per variable[23]. However, to account for missing data and outliers, and to reduce the likelihood of small cell sizes, the recruitment target was increased by 25% to 350.

3.3.2. Measures

An overview of the validated measures can be seen in Table 3.1. The Connor-Davidson Resilience Scale (CD-RISC) measured resilience, the dependent variable of interest[24]. The scale contains 25 questions about personal competence, trust/tolerance/strengthening effects of stress, acceptance of change and secure relationships, control, and spiritual influences. Each item is rated on a 5-point Likert scale from 0 to 4 with higher total scores, ranging from 0 to 100, indicating greater resilience. Quartiles can be used to describe the distribution of the scores with the lowest group (25th quartile) being the least resilient and the highest group (75th quartile) the most resilient. The CD-RISC is a reliable and valid measure of resilience and has been used in several clinical populations[25-27] including MS[14,18,28-30].

Table 3.1. Overview of Validated Instruments Included in Study Questionnaire

Instrument	Construct Measured
Connor-Davidson Resilience Scale (CD-RISC)[24-26,28]	Resilience
Self-report MS Clinical Disease Course Questionnaire[31,32]	Type of MS
Patient Determined Disease Steps (PDDS)[33,34]	Disability Level
Self-report Comorbidity Questionnaire for MS[35,36]	Comorbidities
Health Utilities Index Mark 3 (HUI3)[1,37,38]	Health-related Quality of Life
Daily Fatigue Impact Scale (D-FIS)[39,40]	Fatigue
Hospital Anxiety and Depression Scale (HADS)[41,42]	Anxiety (HADS-A) Depression (HADS-D)
Brief Inventory of Perceived Stress (BIPS)[43,44]	Perceived Stress
Coping with a Disease Questionnaire (CODI)[45-47]	Acceptance Avoidance Cognitive-Palliative Distance Emotional Reaction Wishful Thinking
Multidimensional Scale of Perceived Social Support (MSPSS)[48,49]	Perceived Social Support
Adult Hope Scale (HOPE)[50,51]	Agency – goal setting Pathways – goal planning/execution
Psychological Well-being Checklist (PWB)[52,53]	Self-acceptance Positive Relations with Others Autonomy Environmental Mastery Purpose in Life Personal Growth

The following sociodemographic variables were measured: sex (female/male); age; marital status (married/partner, single/divorced/widowed); highest education level (some/completed high school or some/completed post-secondary) and employment status (working/retired/student/homemaker or not working/able to be a student or homemaker because of MS, including retired due to MS).

The clinical factors were type of MS, disease duration, number of relapses, disability level, comorbidities and fatigue. A graphical representation of the major types of MS (relapsing remitting, primary progressive, secondary progressive), which has been validated against physician classifications of these disease types (kappa = 0.62)[31] and used in other MS studies[32], was used to ascertain type of MS. Disease duration was assessed by asking about age when first experiencing symptoms. The number of relapses in the past 6, 12 and 24 months were collected using the validated definition of relapse developed by the North American Research Committee on MS (NARCOMS) Registry[54]. Disability level was captured using the Patient Determined Disease Steps (PDDS) questionnaire[33], a patient self-report disability level measure that has been used in other MS studies[34]. Respondents indicated their level of disability along a 9-point scale ranging from 0 (normal; some mild symptoms, mostly sensory due to MS, but do not limit activity; if have attack, return to normal after attack has passed) to 8 (bedridden; unable to sit in a wheelchair for more than one hour). The validated Self-Report Comorbidity Questionnaire for MS was used to ascertain the presence or absence of nine commonly found comorbidities in persons with MS (hyperlipidemia, hypertension, heart disease, diabetes, thyroid disease, inflammatory bowel disease, epilepsy, depression, and anxiety)[35, 36].

Fatigue was measured using the Daily Fatigue Impact Scale (D-FIS)[39], containing eight questions which measure the degree to which fatigue causes problems in persons' lives. It provides a summary score from 0 to 32, with higher scores indicating more severe fatigue, and has been validated for use in the MS population[39,40].

The psychosocial factors measured were health-related quality of life (HRQL), anxiety, depression, stress, coping, social support, hope (goal setting, goal planning) and psychological well-being. The validated Health Utilities Index Mark 3 (HUI3), a measure of HRQL, assessed the degree to which the following eight health attributes were affected on a scale of 1 to 6, with 1 being no impact and 6 being severe impact: vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain[37]. In addition to these single attributes, the HUI3 allows for a single multi-attribute score to be tabulated, ranging from 0.0 (death) to 1.0 (perfect health). Negative scores are possible too, indicating states considered worse than death. Overall scores ranging from 0.89-0.99 reflect mild levels of disability on the eight attributes, 0.70-0.88 moderate levels, and scores <0.70 severe levels[55]. People reporting chronic conditions are more likely to be in the moderate and severe disability categories[55]. The HUI3 has been used in the MS population and has strong psychometric properties[1,38].

Depression and anxiety were captured using the 14-item Hospital Anxiety and Depression Scale (HADS)[41]. The seven questions that address anxiety are summed (HADS-A), as are the seven questions that specifically address depression (HADS-D), with total scores ranging from 0-21 for both the HADS-A and HADS-D subscales. Scores are categorized as follows: normal 0-7, mild 8-10, moderate 11-14, and severe 15-21. The HADS has demonstrated reliability and validity in the MS population[42].

Stress was assessed using the Brief Inventory of Perceived Stress (BIPS), a 5-point Likert Scale from 1 to 5[43]. The 9-item BIPS has been validated in MS patients and combines items from the Perceived Stress Scale (PSS)[56] and the Perceived Stress Questionnaire (PSQ)[57]. The scale produces three summary scores: (1) lack of control, (2) pushed (forced into things), and (3) conflict/imposition, as well as an overall score of perceived stress, ranging from 9 to 45, with higher scores equating to greater perceived stress. The BIPS has been used in other MS studies[44].

Coping strategies were captured using the 29-item, 5-point Likert scale based Coping with a Disease questionnaire (CODI)[45,46]. This questionnaire was designed for children and teens with chronic illnesses but is also used in adult chronic illness populations, as the questions apply across the lifespan (e.g., I am able to manage my illness)[47]. The first 28 items collapse into six types of coping strategies: acceptance, avoidance, cognitive-palliative, distance, emotional reaction, and wishful thinking. The 29th question provides an overall coping rating. Acceptance signifies an ability to manage, get used to, cope with, and accept the illness, and use of humour to face the situation[45]. Avoidance refers to ignoring the illness, pretending to be all right, and forgetting about the illness[45]. Cognitive-palliative coping reflects faith, beliefs, being able to think of worse situations, and learning as much as possible about the illness[45]. Distance refers to not caring about the illness, and thinking of the illness as no big deal or not serious[45]. Emotional reaction includes frustration, anger, shame, waking up at night and thinking terrible things, and thinking it was unfair to be ill[45]. Wishful thinking involves wanting to stop having the illness, hoping the illness disappears, and wishing to be healthy[45].

Perceived level of social support was ascertained using the 12-item Multidimensional Scale of Perceived Social Support (MSPSS)[48,49] which has been used in studies assessing the relationship between resilience and support[18,58]. This scale provides an overall score indicating the degree of support received from a significant other, family and friends.

The concept of goal setting and planning was assessed using the Adult Hope Scale[50]. The scale development was informed by Snyder's cognitive model of hope that conceptualizes hope as a cognitive skill demonstrating the ability to sustain drive in the pursuit of particular goals, even in the face of obstacles[59,60]. Hope is thus a positive motivational state, based on two interrelated elements of successful agency related to goals (goal directed energy: *goal setting*) and perceived availability of successful pathways related to goals (sense of ability to generate successful plans to meet goals: *goal planning/execution*)[50]. The scale is based on this framework and consists of eight items, four relating to goal setting and four relating to goal planning/execution. Each item is measured on an 8-point Likert scale, resulting in a possible range of scores between 4.0 and 32.0, with higher scores indicating greater use. This scale has been used as a measure of hope in MS studies[51].

Facets of psychological well-being were assessed using the 18-item Psychological Well-being Checklist (PWB)[52,61], developed under Ryff's model of psychological well-being that encompasses six facets: self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth. Each component has three questions which, when summed, range from 3.0 to 18.0. Higher scores indicate better well-being. The facet of self-acceptance is defined as possessing a positive attitude toward self, acknowledging and accepting multiple aspects of self (including good and bad qualities), and feeling positive about past life[52]. Positive relations with others encompasses having warm, satisfying, trusting relationships with others, being concerned about the welfare of others, capable of strong empathy, affection and intimacy, and understanding the give and take of human relationships[52]. Autonomy is defined as being self-determining and independent, able to resist social pressures to think and act in certain ways, regulate behavior from within, and evaluate self by personal standards[52]. Environmental mastery refers to having a sense of mastery and competence in managing the environment, controlling complex array of external activities, making effective use of surrounding opportunities, and able to choose or create contexts suitable to personal needs and values[52]. Purpose in life is comprised of having goals in life and a sense of directedness, feeling there is meaning to present and past life, holding beliefs that give life purpose, and having aims and objectives for living[52]. Personal growth reflects a feeling of continued development, seeing self as growing and expanding, being open to new experiences, realizing one's own potential, seeing improvement in self and behavior over time, and changing in ways that reflect more self-knowledge and effectiveness[52]. Other MS studies have used this scale for measuring psychological well-being[53,62].

3.3.3. Analysis

Missing items on the CD-RISC, CODI, MSPSS and PWB questionnaires were imputed according to the corresponding developers' recommendations[24,45,48,52]. Descriptive statistics (means, standard deviations [SD], frequencies, and percentages [%]) were used to describe the characteristics of the sample (Table 3.3). Multivariable general linear models were used for determining the sociodemographic, clinical and psychosocial variables associated with CD-RISC scores. The variables listed in Table 3.3 were entered into the model according to their type, continuous or categorical, to determine which factors were associated with greater resilience. An *A priori* decision was made to include sex and age in the model due to these variables' biological and clinical relevance in MS, including their role in the diagnosis and prognosis of MS[63] and in health outcomes such as HRQL[64].

Further, because of the important role of sex and age in MS, sex and age were also assessed to see if they were effect modifiers. Therefore, first-order interactions between sex and the set of variables comprising the final model, as well as between age and the final set, and sex by age were examined. Multicollinearity between the explanatory variables composing the final model was assessed using the tolerance and variance inflation factor (VIF). Variables with a tolerance of <0.20 and/or a VIF >5.00 were removed from the final model. Model assumptions were tested using standard methods[65], and the assumptions of linearity, normality and independence of the resilience outcome measure were met. The data were analyzed using IBM SPSS Statistics version 24.0.

3.4. Results

The first three questions of the “The Resilience in MS Questionnaire” asked the potential participants to confirm that they met the eligibility criteria of: (i) being at least 18 years of age, (ii) having had MS for at least two years and (iii) having a confirmed diagnosis of MS from a doctor. Two persons indicated they did not meet the eligibility criterion of having had MS for at least two years and, therefore, did not continue with the survey. The required sample size was met, with 358 persons with MS meeting the eligibility criteria and completing the questionnaire. The resilience score of the sample is provided in Table 3.2.

Table 3.2. Connor-Davidson Resilience Scale (CD-RISC) Scores

Resilience Scores		Mean (SD*; range)
Overall		72.4 (14.7; 23.0-100.0)
By CD-RISC Quartiles	**25th**	63.0
	50th	72.0
	75th	83.0
By Sex	**Female**	73.5 (14.7; 23.0-100.0)
	Male	69.9 (14.2; 31.0-90.6)
By Age Group Quartiles (in years)		
	25th: 18-39	70.9 (14.2; 67.7-74.1)
	50th: 40-49	73.7 (13.5; 70.6-76.8)
	75th: 50-56	72.1 (15.1; 68.4-75.7)
	100th: 57-77	75.3 (16.0; 71.5-79.1)

*SD=standard deviation

Most of the 358 study participants were female with a median age of 49.0 (Table 3.3). Most participants had relapsing MS with average disease duration since symptom onset of 20.5 years with no one having had MS for less than 2.0 years as per the inclusion criterion. The median disability level was 2.0 on the Patient-Determined Disease Scale (PDDS), reflecting mild disability *(“some noticeable symptoms from MS, but they are minor and have only a small effect on lifestyle”*[33]). Most participants reported ≥1 relapse in the past 24 months, and the most common comorbidity was depression. The average scores on the anxiety (HADS-A) and depression (HADS-D) scales reflected mild levels. Most of the sample had moderate fatigue (D-FIS) and stress (BIPS) scores. The average overall social support (MSPSS) score indicated the participants mildly to strongly agreed they had supportive significant others, family and friends. The average HUI3 score, 0.6, fell into the severe disability category, reflecting a low overall health-related quality of life.

The average score on the overall coping question was high (4.2). Coping strategies of acceptance, avoidance, cognitive-palliative and wishful thinking had the highest use. Agency (goal setting), and pathways (goal planning/execution), as measured by the HOPE scale, had similar average scores of 24.5 and 24.8 respectively out of a possible high score of 32.0. Of the six PWB sub-scales, personal growth had the highest average score, followed by autonomy, purpose in life, self-acceptance, environmental mastery and positive relationships with others.

Table 3.3. Cross-sectional Study Sample Characteristics

Characteristic		n, %†
Sex	**Female**	229 (79.2)
	Male	60 (20.8)
Marital Status	**Single/Divorced/Widowed**	72 (25.0)
	Married/Partner	216 (75.0)
Education Status	**High School or Below**	108 (37.0)
	Post-Secondary	184 (63.0)
Employment Status	**Working/Employable**	158 (54.1)
	Not Working Due to MS	134 (45.9)
Disease Course	**Relapsing-Remitting§**	170 (61.4)
	Primary or Secondary Progressive	107 (38.6)
Relapse in Past 24 Months	**Yes**	203 (70.5)
	No	85 (29.5)
At Least 1 Comorbid Condition	**Yes**	131 (50.0)
	No	131 (50.0)

Characteristic	Mean (SD; range)‡
Age	48.2 (11.7; 21.0-77.0)
Clinical Measures	
Disease Duration Since Symptom Onset	20.5 (11.7; 2.0-57.0)
Disability Level (PDDS*)	2.7 (2.4; 0.0-8.0)
HRQL (HUI3*)	0.6 (0.3; -0.3-1.0)
Fatigue (D-FIS*)	12.5 (7.6;0.0-32.0)
Anxiety (HADS-A*)	10.0 (2.5; 5.0-16.0)
Depression (HADS-D*)	8.4 (1.6; 4.0-13.0)
Stress (BIPS*)	26.3 (7.0; 9.0-45.0)
Social Support (MSPSS*)	65.0 (16.3; 12.0-84.0)
Coping (CODI*)	
Acceptance	3.8 (0.7; 1.2-5.0)
Avoidance	3.2 (0.7; 1.3-4.8)
Cognitive-Palliative	3.0 (0.8; 1.4-5.0)
Distance	2.3 (0.9; 1.0-5.0)
Emotional Reaction	2.4 (0.8; 1.0-5.0)
Wishful Thinking	4.1 (1.0; 1.0-5.0
Overall	4.2 (1.0; 1.0-5.0)
Characteristic	**Mean (SD; range)‡**
Hope	
Agency (goal setting)	24.5 (5.2; 6.0-32.0)
Pathways (goal planning/execution)	24.8 (4.8; 4.0-32.0)
Psychological Well-being	
Autonomy	13.7 (2.6; 4.5-18.0)
Environmental Mastery	13.5 (3.2; 3.0-18.0)
Personal Growth	15.2 (2.8; 4.5-18.0)
Positive Relations with Others	11.1 (1.8; 8.0-18.0)
Purpose in Life	13.7 (3.1; 3.0-18.0)
Self-acceptance	13.6 (3.5; 3.0-18.0)

*PDDS=Patient Determined Disease Steps; HUI3=Health Utilities Index Mark 3; D-FIS=Daily Fatigue Impact Scale; HADS-A=Hospital Anxiety and Depression Scale-Anxiety; HADS-D=Hospital Anxiety and Depression Scale-Depression; BIPS=Brief Inventory of Perceived Stress; MSPSS=Multidimensional Scale of Perceived Social Support; CODI=Coping with a Disease Questionnaire

†Missing data: 65 cases missing from age; 69 from sex; 72 from marital status; 66 from employment and education; 81 from MS type; 71 from PDDS, 96 from comorbidity; 71 from HUI3; 63 from D-FIS; 16 cases missing from acceptance and avoidance; 15 from cognitive-palliative; 19 from distance and emotional reaction 20 from wishful thinking; 22 from cope overall; 28 from support; 35 from hope agency and pathways; 61 from HADS anxiety and depression; 60 from BIPS; 16 from self-acceptance; 15 from positive relations; 8 from autonomy; 9 from environmental mastery; 15 from purpose in life; 10 from personal growth

‡SD refers to standard deviation; range refers to range in the study sample; % refers to valid percent

§Relapsing refers to relapses with and without complete recovery between attacks, but stability between attacks; Progressive refers gradual worsening of disease either from start of disease or later in course of disease[31]

Using a multivariable general linear model, the factors associated with greater resilience were: older age; greater use of acceptance and cognitive/palliative (thinking/belief) coping strategies; hope (higher use of goal setting and goal planning strategies); and greater psychological well-being (higher scores on PWB autonomy, environmental mastery, personal growth and self-acceptance sub-scales) (Table 3.4). Sex is reported in the final model due to its biological relevance and clinical importance in MS[63,64]. However, the association between sex and resilience was not statistically significant. Together, these variables explained 76.1% of the variance in resilience with goal setting explaining 52.9% of the variance. None of the variables demonstrated sufficient collinearity to be removed. In addition, none of the first-order interactions assessed, sex by age, sex by any of the other independent variables in the final model, or age by any of the final variables, were statistically significant.

Table 3.4. Multivariable General Linear Model Results

Factor	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error			
Sex	1.14	1.08	0.03	1.06	0.29
Age	0.08	0.04	0.06	2.08	0.04
Coping – Acceptance	4.33	0.75	0.21	5.82	≤ 0.01
Coping – Cognitive Palliative	2.96	0.53	0.17	5.55	≤ 0.01
Hope – Agency (Goal Setting)	0.45	0.15	0.16	3.00	≤ 0.01
Hope – Pathways (Goal Planning)	0.62	0.14	0.20	4.32	≤ 0.01
PWB* – Autonomy	1.05	0.18	0.19	5.85	≤ 0.01
PWB – Environmental Mastery	0.68	0.20	0.15	3.45	≤ 0.01
PWB – Personal Growth	0.57	0.21	0.11	2.73	≤ 0.01
PWB – Self-acceptance	0.67	0.18	0.16	3.70	≤ 0.01

*PWB=Psychological well-being

3.5. Discussion

The purpose of this study was to assess resilience among persons with MS and to determine what sociodemographic, clinical and psychosocial factors were associated with greater resilience in people with MS. The average resilience score in this sample of persons with MS was 72.4. In comparison to scores obtained during the original validation study of the CD-RISC (conducted in the US), this score is lower than the general population sample (80.7), similar to primary care patients (71.8), and higher than psychiatric outpatients (68.0), generalized anxiety outpatients (62.4), and post-traumatic stress disorder outpatients (47.8 and 52.8)[27]. However, the authors of the CD-RISC caution that location / region where the data are obtained influences scores[27]. The CD-RISC has been used to study resilience in a variety of Canadian populations including the general population, students, youth, young adults, those with psychiatric disorders and those with medical problems[27]. To date, resilience scores reported among Canadians are highest in community-dwelling older adults aged 60+ (men 80.0; women 77.5)[66] and lowest in Canadian vulnerable youth (e.g., homeless males 60.9, homeless females 53.1)[67] and those with psychiatric disorders (e.g., depressed bipolar patients 43.3)[68]. Other reported Canadian resilience scores include those with moderate to severe traumatic brain injury (80.0, 45-64 years of age; 70.0, 19-44 years of age)[69], primary care patients (75.8)[70], those with epilepsy (73.3)[71], farmers (71.1)[72] and chronic back pain patients (65.1)[73].

The finding that participants in this study had lower scores than the published scores for Canadian community-dwelling older adults and primary care patients is not surprising given that MS is a chronic progressive disease. However, that participants in the current study achieved scores similar to that of Canadian farmers, a non-disease specific group, is interesting.

Participants in the farmers study had high stress due to unpredictable weather, animal disease, economic stresses, overwork, burden of paperwork / bureaucracy, media criticism and social isolation[72]. Many of these stressors are impossible for farmers to control or change. Likewise in MS, there are many factors that are impossible for persons living with it to control or change, such as what part(s) of the central nervous system will be affected[74,75]. Unpredictability may play an important role in resilience, regardless of the population under study[76,77].

This study's sample had a higher score than chronic back pain patients[73]. The low resilience score amongst chronic back pain patients gives rise to the question the role pain may have in the resilience of persons with MS. Research regarding pain and resilience to date has tended to investigate the effect of resilience on pain outcomes in those with various health conditions, including MS[78], rather than the potential effect of pain on resilience. For example, a recent study examined the relationships among positive affect, resilience and pain measures in MS and found resilience mediated the associations between positive affect and pain intensity[29]. As this study was cross-sectional in nature, causal determinations were not feasible. However, the authors concluded that pain can have a negative impact on the physical and psychosocial functioning of persons with MS, and thus, further research, including longitudinal studies, is warranted to better understand the strength and direction of the relationship between pain and resilience to ultimately improve patient outcomes[29].

The CD-RISC resilience score in this study is similar to the CD-RISC resilience score found in a study examining the relationships among mindfulness and perceived stress, coping, and resilience in people with MS (73.4)[28]. The study on pain and resilience in MS discussed in the previous paragraph reported a mean CD-RISC-10 score of 28.8 which would equate to about 72.1

on the CD-RISC-25[29]. The CD-RISC-10 is a condensed version of the original CD-RISC 25-item questionnaire. The CD-RISC-10 has a possible range of 0.0 to 40.0 compared to the CD-RISC-25 which has a possible of range from 0.0 to 100.00[79]. A lower CD-RISC-10 score, 26.8 (approximately 67.0 on the CD-RISC-25), was found in a study examining the role of resilience as mediator in social support and mental health outcomes[18]. However, to be eligible for this particular study, the participants had to have substantial levels of depression and/or fatigue and/or pain, and thus, this could account for the lower score. These three studies on resilience in MS, the mindfulness, pain, and social support and mental health studies, were conducted in the US. A study of Australian persons with MS also resulted in a lower resilience score on the CD-RISC-10, 27.0, than this study's (about 67.5 on the CD-RISC-25)[14]. The study included persons newly diagnosed with MS (less than 1 year), whereas the present study excluded persons diagnosed for less than two years, as the first couple of years can be a difficult time of adjustment[10,22]. In a study of Iranian persons with MS, the CD-RISC-25 score was lower at 57.5 than this study's[30]. However, it is important to view this number in comparison to the Iranian healthy controls score, which was only 65.1[30]. The variation in the scores amongst the US, Australian and Iranian MS studies reinforce the CD-RISC developers' assertion that scores are influenced by location / region[24]. It should also be noted that no minimal clinically important difference score has been established for the CD-RISC, and thus, it is unclear whether the differences in scores are meaningful[27]. To the best of this author's knowledge, this is the first study to report a CD-RISC-25 score for Canadians with MS.

The second aim of this study was to determine what sociodemographic, clinical and psychosocial factors are associated with greater resilience in people with MS. In our model, nine factors were associated with higher resilience adjusted for sex: *older age, more use of acceptance and cognitive/palliative (learning/faith) coping strategies, more goal-setting and goal-planning/execution strategies (greater hope), and higher autonomy, environmental mastery, personal growth and self-acceptance (greater psychological well- being).*

The association between older age and higher (better) levels of resilience in this study is supported by other research, and it has been suggested that young and mid-adulthood may be times when persons with MS are particularly vulnerable to lower levels of resilience[17,19,64,80]. The authors of a small pilot study investigating the effect of a positive psychology program on resilience in MS patients 45 years of age and older, cited the reason for targeting this age group was that mid-adulthood brings the simultaneous challenge of coping with advancing MS alongside age-related changes[21]. Studies focusing on aging with MS have suggested that older persons with MS adjust to and cope with MS better than young and middle-aged persons with MS[81-83]. However, it should be noted that most of these findings are from cross-sectional studies, and it is unclear whether growing older actually leads to increased resilience. One alternative explanation for these findings is the birth cohort effect (i.e., older individuals have greater resilience because of a shared temporal or life experience).

However, the lower resilience in younger age groups may be due to this being a period of time when persons with MS are learning how to live with a chronic disease while juggling other roles and responsibilities and facing potential changes in their employment, societal and family roles and responsibilities. Young adulthood may be an especially difficult time for women, given the challenges of learning how to live with a chronic disease while managing a young family, work and home[17,19,64,80]. Women also tend to have an earlier age of onset compared to men[84]. Perhaps for men, a more challenging time with a greater need for resilience interventions might be when they are in mid-adulthood. Men with MS in mid-adulthood may no longer be able to fulfill their work or household responsibilities to the extent they had previously and tend to experience progression faster than women[17,19,64,80]. The relationship between aging and resilience is an interesting one that requires longitudinal investigation to determine the strength and direction of the relationship. Resilience has been reported to be a foundational factor for healthy aging in a qualitative study exploring factors associated with healthy aging in MS[19]. Whether aging leads to greater resilience or greater resilience leads to healthier aging is an important question for further research.

The association found between certain types of coping (i.e., acceptance and cognitive-palliative) and resilience is consistent with other research findings that these types of coping strategies (i.e., "adaptive", active" or "problem solving") are generally associated with better adjustment to MS related challenges, better health related quality of life, less depression and less anxiety in those with MS[85-90]. Faith, one aspect of cognitive-palliative coping, has also been shown to be positively associated with help-seeking behaviors, an adaptive reappraisal strategy and gratitude in persons living with MS[91,92]. There has been little prior research on the role of coping in resilience of those with MS. However, relevant evidence comes from one small intervention study conducted with persons with MS. In that study, a type of cognitive-behavioral therapy (Acceptance and Commitment Therapy: ACT) which is aimed at enhancing acceptance, cognitive defusion (learning to allow problematic thoughts or feelings to arise without functioning in problematic ways), mindfulness, self-awareness, values (beliefs/faith) and committed action, led to greater resilience in participants along with decreased psychological distress and improved quality of life[93]. Given this evidence, along with the well documented association between active, problem solving types of coping and positive outcomes, the current findings suggest that acceptance and cognitive-palliative (learning/beliefs) coping should be considered important resources in the resilience of those with MS.

In the current study, two aspects of hope (goal setting and goal planning/execution) were also associated with greater resilience, and variance in the subtest score, *goal setting,* explained most of the variance in resilience scores. Although the association between hope and resilience has received little study in those with MS, this association has been shown to be present in those with other types of physical illnesses. In a study involving adolescents and young adults with cancer, an intervention (Promoting Resilience in Stress Management (PRISM)), which included stress management, goal setting, cognitive reframing and meaning making, resulted in improved patient reported resilience, quality of life and psychological distress[94]. Hope, resilience and social support are also positively associated with quality of life in those with bladder cancer and renal carcinoma[95,96]. In a study of psychological distress among stroke patients, hope and resilience were found to be associated with less depressive symptoms[97]. Goal reengagement strategies (extent to which one considers oneself able to reengage in alternative meaningful goals in the case that preexisting goals are no longer reachable) were associated with positive refocusing (thinking about joyful and pleasant issues instead of thinking about the negative experience) and lower depressive symptoms in patients recovering from first-time myocardial infarctions[98]. Evidence of the association between hope (goal setting and planning/execution) and resilience in the above studies and in this study points to a new avenue for research in MS: To what extent might interventions aimed at enhancing hope alone strengthen resilience among persons with

MS? Encouraging persons with MS to believe they can set goals and work toward them has the potential to significantly offset the negative impact of their vulnerabilities[34,85,99].

Psychological well-being (as assessed through autonomy, environmental mastery, personal growth and self-acceptance) was associated with greater resilience. In the literature on resilience and psychological well-being, resilience is typically explored as a potential resource for psychological well-being[100,101]. For example, in a study of nursing students, higher resilience was positively associated with greater psychological well-being[102]. In a study of community-dwelling young and mid-aged adults, aspects of well-being (positive relations with others, autonomy, environmental mastery, and personal growth) were associated with greater resilience[103]. Similarly, in a study with adolescents, psychological well-being was associated with greater resilience[104].

In this study, autonomy was associated with resilience. Autonomy among persons with MS is often thought about in terms of physical independence or an ability to sustain ambulation and carry out activities of daily living[105]. However, other kinds of autonomy, including maintaining the capacity for decision making and autonomy in social interactions, are also important for persons with MS[106]. Physical rehabilitation programs and assistive devices improve the ability of persons with MS to maintain independence even in the face of progressing disability[107]. Likewise, cognitive rehabilitation programs for those with MS are shown to improve the skills and strategies needed to manage the cognitive dysfunction that can accompanying MS[108,109].

In a similar way, environmental mastery, being able to manage one’s own environment and make use of opportunities, also supports the need for programs and services to help persons with MS to do this. Employment and living situations often require adjustment and an ability to navigate governmental and health care systems and community supports[9,110]. The processes one must go through to receive long-term disability income, home care services, and necessary equipment (e.g., bathroom grab bars and air conditioners to deal with heat intolerance) can be tedious and intimidating without resources to help guide and inform[19,111,112].

Two additional aspects of psychological well-being, self-acceptance and personal growth, were also found to be associated with resilience in this study. These align well with the sustainability and growth facets in resilience theory: (i) maintaining a sense of purpose and meaning within the context of a chronically changing and stress-ridden life and (ii) the ability to gain new insights and enhance one's capacity for overcoming difficult and ongoing stressors. Thus, resilience, by definition, requires acceptance of the past and present to develop successful strategies and mechanisms for adapting to and coping with the variable and progressive nature of MS. As discussed earlier in regard to acceptance coping, acceptance was a component of an ACT intervention study that resulted in greater resilience among MS participants[93]. In a systematic review of post-traumatic growth (enhancement in previous level of psychosocial functioning as a result of coping with traumatic events, a key facet of resilience) in people living with cancer, HIV/AIDS, cardiac disease, rheumatoid arthritis or MS, growth was found to be associated with fewer depressive and anxiety symptoms and less distress[113].

What is perhaps surprising in this study was the exclusion of social support as a factor associated with greater resilience. However, a study examining predictors of adjustment to MS found no association between social support and adjustment[14]. The authors suggested one explanation for this anomaly. That is that they had focused on support provided by family and friends instead of support provided by health care professionals and others outside of close family and friends. Those sources of social support may be critical for persons with MS, and further research regarding these other potential sources of support is warranted. This same rationale may apply to the current study in that the measure used also focuses on significant others, family and friends[48]. A Canadian review of resilience definitions and factors contributing to it suggests social support beyond family and friends does need to be considered [114]. Further research regarding other sources of social support and their association with resilience in MS is warranted. An additional thought regarding social support in the context of resilience and chronic diseases such as MS is that relationships can often be strained and caregivers can often feel burdened[115,116]. There may be complexities to the association between familial social support and resilience that also require attentive investigation.

Four limitations of this study need to be noted. Participants were volunteers who may have been interested in the concept of resilience and who believed they were resilient. Thus, the average CD-RISC score of 72.4, although similar to scores obtained in other studies with similar sample characteristics, may be higher than an average score obtained from a more diverse MS population[28,29]. Due to the study inclusion criteria, these findings may not generalize to youth with MS, those newly diagnosed with MS (less than 2 years), the cognitively impaired or the severely disabled, and/or those in long-term care settings. The clinical characteristics of the sample, including type of MS, disease duration, number of relapses, disability level and comorbid diseases were self-reported thus the possibility of misclassification exists, although such misclassification is not likely to be systematic. The cross-sectional nature of this study precludes causal inference. Therefore, longitudinal studies are needed to understand the causal pathways between potential resources and vulnerabilities and resilience.

3.6. Conclusions

The results from this study represent a first step in understanding resilience in persons with MS. Further research is needed to confirm this study's findings, and in particular, longitudinal studies would facilitate our understanding of how sociodemographic, clinical and psychosocial factors may impact resilience over time. Additionally, research is needed to assess how resilience and changes in resilience impact the health and well-being of those with MS. Coping, hope and psychological well-being are important psychological constructs that were associated with resilience in this group of persons with MS. Developing a better understanding of the role these constructs play in resilience and what role resilience plays in enhancing the lives of those with MS are research directions that hold promise for decreasing the vulnerabilities and burdens associated with MS.

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CHAPTER 4

Manuscript Title: Factors analysis of the Connor-Davidson Resilience Scale (CD-RISC) in MS

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CHAPTER 4: Factor Analysis of the Connor-Davidson Resilience Scale (CD-RISC) in MS (Study 2)

4.1. Chapter Synopsis

Background: The Connor-Davidson Resilience Scale (CD-RISC-25) is one of the most widely known and utilized measures of resilience in both general and disease-specific populations. The 25 questions are summed to provide a resilience score. A factor analysis of the scale extracted five factors: personal competence and tenacity; trust and tolerance; positive acceptance of change; control; and spiritual influences. Factors analyses of the scale in other populations have shown that the 25 questions tend to group together differently, suggesting there may be somewhat unique underlying structures of resilience for each particular population. As resilience research in MS is beginning to grow, understanding the factor structure of the CD-RISC-25 in the MS population is important in operationalizing the definition of resilience. A condensed version, the CD-RISC-10, is also available for measuring resilience. A factor analysis of this shortened version has revealed that the 10 questions group together as one factor, resilience. Since both versions are apt to be used as measures of resilience in future descriptive, exploratory and interventional research, an investigation of the psychometric properties of the scales is needed. ***Purpose:*** The aim of this study was to explore the factor structure of the CD-RISC-25 and CD-RISC-10 in persons with MS and to establish the reliability across items (internal consistency) and construct validity of the scales. ***Methods:*** Participants who completed all 25 questions of the CD-RISC-25 in the cross-sectional survey (Paper 1) formed the study sample for this study (N=322). Exploratory (EFA) and confirmatory (CFA) factor analyses were conducted on both the CD-RISC-25 and CD-RISC-10. Cronbach's alphas were calculated for assessing the internal consistency of both the scales' overall scores as well as the proposed sub-scales (factors) emerging from the EFA. The construct validity of the CD-RISC-25 and CD-RISC-10 were assessed through hypothesis testing that the higher resilience overall score and sub-scales emerging from the factor analyses would be positively correlated with health (i.e., the sub-scales of the Health Utilities Index Mark3 (HUI3) and the Psychological Well-being (PWB) checklist). ***Results:*** Five factors emerged from the EFA of the CD-RISC-25: *positive acceptance of change*, *personal competence*, *secure in oneself and others*, *perseverance*, and *spiritual influences*. This five-factor model was assessed with CFA goodness of fit statistics as was the one-factor model that emerged for the CD-RISC-10 (*resilience)*. The Cronbach's alpha values for the CD-RISC-25 and CD-RISC-10 total scores were 0.93 (95%CI: 0.92, 0.94) and 0.89 (95%CI: 0.87, 0.91) respectively. The overall resilience scores of both scales had correlations with the HUI3 and PWB sub-scales ranging from 0.36 to 0.67 and a range of -0.05 to 0.69 for the factors emerging from the EFAs. ***Conclusions:*** The CFA goodness of fit statistics for the CD-RISC-25 five-factor model were fairly good but did fall shy of the conventional statistical criteria for a good fit model. The CFA CD-RISC-10 unidimensional factor model performed better. The internal consistency of both scales was excellent. A mix of low and moderate strength correlations were found for the CD-RISC-10 and the first four factors of the CD-RISC-25 EFA. The fifth factor, spiritual influences, had negligible correlations. The majority of the correlations among the overall resilience scores of the CD-RISC-25 and HUI3 and PWB were moderate in strength. Both the CD-RISC-25 and CD-RISC-10 are reliable measures of resilience in MS. The underlying factor structure arising from the EFA provides some sense of what may be the most salient features of resilience for persons living with MS.

4.2. Introduction

Resilience is an important concept in the clinical research literature on psychological well-being and chronic disease[1-3]. Generally viewed as a process through which individuals positively adapt to adversity, resilience facilitates a sense of health and well-being amidst difficult and ongoing stressors[4,5]. To understand resilience from an operational perspective, clinicians and researchers have attempted to discover the underlying factors or common processes composing resilience[1,4,6]. This understanding helps generate ideas about how to strengthen resilience in persons living with chronic diseases.

The most common measure used to assess resilience in various general and clinical populations is the Connor-Davidson Resilience Scale[7] (CD-RISC-25) (Figure 4.1). While this 25-item scale was designed to yield a single score, the authors assessed the factor structure of the measure in a general United States (US) population and found the items clustered into five factors: personal competence, high standards and tenacity; trust in one's instincts, tolerance of negative effects and strengthening effects of stress; positive acceptance of change; control; and spiritual influences[7]. These factors have helped shape some of the theories and intervention approaches aimed at increasing resilience amongst both general and disease populations[1,4,5].

Since then, the factor structure of the CD-RISC-25 has been assessed in other populations, and those findings reflect some similarities to the above factor structure in terms of the number and the names of the factors. However, most studies have not replicated the original exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) results.

Figure 4.1. Connor-Davidson Resilience Scale-25* (CD-RISC-25) (Items composing CD-RISC-10 in bold)

Instructions: For each item, please mark with an "x" in the box below that best indicates how much you agree with the following statements as they apply to you **over the last month**. If a particular situation has not occurred recently, answer according to how you think you would have felt.

	Not true at all	**Rarely true**	**Some-times true**	**Often true**	**True, nearly all the time**
1. I am able to adapt when changes occur.	☐	☐	☐	☐	☐
2. I have at least one close and secure relationship that helps me when I am stressed.	☐	☐	☐	☐	☐
3. When there are no clear solutions to my problems, sometimes fate or God can help.	☐	☐	☐	☐	☐
4. I can deal with whatever comes my way.	☐	☐	☐	☐	☐
5. Past successes give me confidence in dealing with new challenges and difficulties.	☐	☐	☐	☐	☐
6. I try to see the humorous side of things when I am faced with problems.	☐	☐	☐	☐	☐
7. Having to cope with stress can make me stronger.	☐	☐	☐	☐	☐
8. I tend to bounce back after illness, injury, or other hardships.	☐	☐	☐	☐	☐
9. Good or bad, I believe that most things happen for a reason.	☐	☐	☐	☐	☐
10. I give my best effort no matter what the outcome may be.	☐	☐	☐	☐	☐
11. I believe I can achieve my goals, even if there are obstacles.	☐	☐	☐	☐	☐

	Not true at all	**Rarely true**	**Some-times true**	**Often true**	**True, nearly all the time**
12. Even when things look hopeless, I don't give up.	☐	☐	☐	☐	☐
13. During times of stress/crisis, I know where to turn for help.	☐	☐	☐	☐	☐
14. Under pressure, I stay focused and think clearly.	☐	☐	☐	☐	☐
15. I prefer to take the lead in solving problems rather than letting others make all the decisions.	☐	☐	☐	☐	☐
16. I am not easily discouraged by failure.	☐	☐	☐	☐	☐
17. I think of myself as a strong person when dealing with life's challenges and difficulties.	☐	☐	☐	☐	☐
18. I can make unpopular or difficult decisions that affect other people, if it is necessary.	☐	☐	☐	☐	☐
19. I am able to handle unpleasant or painful feelings like sadness, fear and anger.	☐	☐	☐	☐	☐
20. In dealing with life's problems, sometimes you have to act on a hunch without knowing why.	☐	☐	☐	☐	☐
21. I have a strong sense of purpose in life.	☐	☐	☐	☐	☐
22. I feel in control of my life.	☐	☐	☐	☐	☐
23. I like challenges	☐	☐	☐	☐	☐
24. I work to attain my goals no matter what roadblocks I encounter along the way.	☐	☐	☐	☐	☐
25. I take pride in my achievements.	☐	☐	☐	☐	☐

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For example, in a study of adults ≥ 60 years of age with major depressive disorder, four factors emerged instead of five, named by the authors as grit, active coping self-efficacy, accommodative coping self-efficacy and spirituality[8]. Likewise, in a study of older women in the US, a different set of four factors emerged which those authors called personal control and goal orientation, adaptation and tolerance for negative effect, leadership and trust in instincts, and spiritual coping[9]. In a study of resilience amongst critical care nurses in the US, three factors emerged which the authors termed competence, perseverance and leadership[10]. This variability in factor structure has given rise to the idea that resilience components may manifest themselves differently in different populations[11-13].

The differing results have also given rise to the question of whether a subset of items from the CD-RISC-25 might lend themselves to a more consistent, reliable and valid construct of resilience across study populations. Based on this research question, a factor and psychometric analysis of the CD-RISC-25 was conducted using a large sample of American undergraduate students[14]. The complete sample was split into three groups: Samples 1 and 2 to conduct two independent EFAs to determine if similar results could be achieved and Sample 3 for the CFA. The EFAs resulted in differing factor structures despite the two samples being demographically equivalent and similar in size. However, 10 questions had strong and similar factor loadings in both EFAs. A CFA of these 10 items (questions 1, 4, 6, 7, 8, 11, 14, 16, 17 and 19 from the original) resulted in a structure that fit the data well and demonstrated strong psychometric properties. These authors used the 10 items to form the CD-RISC-10 resilience scale. This condensed version has been used in other general and disease populations, providing a unidimensional measure of resilience with strong psychometric properties[15-17]. Similar to the factors emerging from the original factor analysis of the CD-RISC-25, the specific items composing the CD-RISC-10 (i.e., able to adapt to change, see humorous side, can achieve goals, can handle unpleasant feelings) have served as the underpinnings of resilience-based interventions[5,11,18].

Developing potential interventions for strengthening resilience is an area of clinical care and research in multiple sclerosis (MS)[19,20], the leading non-traumatic cause of chronic neurological disability amongst young adults worldwide[21,22]. Most affected individuals experience the onset of symptoms between the ages of 20 and 40 years[23]. As the disease is characterized by inflammation and degeneration of the central nervous system, symptoms are many and variable, including impaired gait and ambulation, weakness, fatigue, cognitive difficulties, vision issues, bladder/bowel dysfunction and sensory impairments. These symptoms can result in episodic and permanent disability. Although medications can modify the disease, there are currently no curative treatments. Thus, persons with MS need to adapt to a life of living with a chronic disease.

To best understand resilience in specific populations, such as those with MS, understanding the underlying factor structure may help to illuminate the salient resilience processes that are important to that population[24,25]. The primary aim of this study was to explore the factor structure of both the CD-RISC-25 and CD-RISC-10 amongst persons with MS using EFA and CFA and compare the model fit between the two. A secondary aim was to establish the reliability across items (internal consistency) and construct validity of the CD-RISC-25 and CD-RISC-10 in an MS sample. With regard to construct validity, it was hypothesized that those with higher resilience scores would have higher health-related quality of life (HRQL) and psychological well-being (PWB) scores based on research findings in the literature that demonstrate the positive impact of resilience on psychosocial outcomes such as HRQL and PWB[19,20,26,27]. Any and all resilience factors emerging from the EFA and CFA, along with the total scores of both the CD-RISC-25 and CD-RISC-10, were examined to see if higher/better resilience scores were positively correlated with the higher/better HRQL and PWB scores.

4.3. Methods

4.3.1. Participants and Procedures

Data were from a cross-sectional study designed to assess sociodemographic, clinical and psychosocial factors associated with greater resilience amongst persons with MS[28]. Recruitment for the cross-sectional study occurred from March 2015 to April 2016. Participants were recruited via posters placed in three MS specialty clinics in Alberta, Canada; a mail-out to those patients who had previously consented to being contacted about research studies at a fourth MS clinic in Manitoba; and through the MS Society of Canada's print and e-newsletters. Interested patients received an informational handout that included a web address and quick response (QR) scan code for completion of an online survey which included the CD-RISC-25. Paper and pencil versions were also available. The University of Alberta and University of Manitoba's Health Research Ethics Boards approved the study (Appendices A and B).

Inclusion criteria were: (1) age ≥18 years, (2) English-speaking, (3) self-report of a confirmed diagnosis of MS by an MS specialist, (4) self-reported confirmation of having MS for at least two years since symptom onset, and (5) self-reported ability to complete the questionnaire independently. Those newly diagnosed with MS were not included as the initial time following diagnosis can be an especially challenging time of adjustment to living with a chronic disease[29]. The recruitment posters, information handouts, newsletters, and introductory page of the questionnaire listed the eligibility criteria. The participants' adherence with the inclusion criteria was via self-report, as the survey was designed to be anonymous to reduce the possibility of response bias. The responses were collected in an EXCEL spreadsheet managed by the University of Alberta Evaluation and Research Services. Paper responses were entered manually.

As a general rule, variables that are subjected to a factor analysis should each have at least 5 to 10 observations[25]. With 25 questions composing the CD-RISC-25, a minimum sample of 125 completed questionnaires would be required. The 358 persons with MS who completed the original study (Paper 1), providing a sufficient sample size to conduct the EFA and CFA as well as the reliability (internal consistency) statistics. To examine the construct validity of the CD-RISC-25 and CD-RISC-10, the hypothesis testing approach was employed[30]. Higher/better resilience scores were postulated to be positively correlated with higher/better scores in related constructs and, in particular, the emotion and multi-attribute aspects of HRQL and psychological well-being[19,20,26,27].

4.3.2. Measures

Each of the 25 questions composing the CD-RISC-25 is scored on a 5-point Likert-type scale with the following response options: not true at all (0), rarely true (1), sometimes true (2), often true (3), and true nearly all the time (4). This resulted in a possible score range of 0 to 100 with higher scores indicating greater resilience. Each question is based on how the participant has felt over the past month. The original psychometric properties of the CD-RISC-25 in the general population and patient samples supported its internal consistency, test-retest reliability and convergent and divergent validity[7].

In addition to the CD-RISC-25, the validated Health Utilities Index Mark 3 (HUI3) and Psychological Well-being (PWB) checklist were administered. The HUI3 assesses the degree to which the following eight health attributes are affected on a scale of 1 to 6 with 1 being no impact and 6 being severe impact: vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain[31]. A utility score is obtained for each of these eight attributes along with an overall multi-attribute score (0.0-death to 1.0-perfect health). Negative scores are possible too, indicating states considered worse than death. Overall scores ranging from 0.89-0.99 reflect mild levels of disability on the eight attributes, 0.70-0.88 moderate levels, and scores <0.70 severe levels[32]. People reporting chronic conditions are more likely to be in the moderate and severe disability categories, reflecting poorer HRQL[32]. There are six facets to the PWB checklist: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance[33]. Possible scores range from 3.0 to 21.0 for each of the facets, as each component has three questions asking the participants to indicate the degree to which they agree with the statement on a Likert-type scale from 1 to 7. Higher scores equal better PWB.

The questionnaire also asked participants to indicate their sex, age, marital status (married/partner or single/divorced/widowed), highest education level (some/completed high school or some/completed post-secondary) and employment status (working/retired/student/ homemaker or not working/able to work/be a student or homemaker due to MS, or retired due to MS). Validated self-report measures also assessed the participants' perceived disease course (relapsing-remitting, primary progressive or secondary progressive)[34], relapse in past 24 months (yes/no)[35], and disability level via the Patient Determined Disease Steps (PDDS)[36]. The PDDS is an ordinal nine-point scale with higher scores indicating more severe disability. Disease duration was assessed by asking about age when symptoms were first experienced. In addition, the validated Self-Report Comorbidity Questionnaire for MS was used to ascertain the presence or absence of nine common comorbidities in persons with MS (hyperlipidemia, hypertension, heart disease, diabetes, thyroid disease, inflammatory bowel disease, epilepsy, depression and anxiety)[37].

4.3.3. Analysis

The aim of this study was to study this measure's psychometric properties (factor structure, reliability, validity) in those with MS. Thus, only those participants who completed all 25 questions of the CD-RISC-25 were included. Imputation of missing test items may have allowed for a small increase in the sample size. However, since this study focused on the test's psychometric properties, imputing scores of missing items might have artificially inflated indices of reliability and validity and, thus, affected the factor structure findings. To evaluate whether non-completion introduced response bias, differences in sociodemographic and disease characteristics between those who did and did complete the CD-RISC-25 using binary logistic regression models were examined.

For the exploratory and confirmatory factor analyses, the study sample was randomly split into two sub-samples using the random split file function available in the IBM SPSS Statistics version 24.0 software. Sample 1 was used to conduct the EFA of the 25-item CD-RISC-25 and CD-RISC-10, while sample 2 was used to verify the factor structure obtained from the EFA using CFA. For the EFA, principal axis factoring and oblique Promax rotation were used as it was anticipated the 25 factors of the CD-RISC-25 would be correlated. Bartlett's test of sphericity was evaluated for the factorability of the questions (significant level of $p < 0.05$), and the Kaiser-Meyer-Oklin (KMO) measure of sampling adequacy was also evaluated to determine the suitability of this sample for EFA (cut-off above 0.50). An eigenvalue of ≥ 1.0 was used as the criterion for factor extraction. General factor loadings were considered meaningful if they exceeded 0.32[25].

The first step in the CFA process was to test the factor structure emerging from the CD-RISC-25 and CD-RISC-10 EFAs. Maximum-likelihood minimization functions were employed using

IBM SPSS AMOS version 24.0 software. Goodness of fit was evaluated using the standardized root mean square residual (SRMR), root mean square error of approximation (RMSEA), comparative fit index (CFI), and the chi-square test with p value and degrees of freedom (SRMR ≤0.08, RMSEA≤0.06, CFI≥0.95)[25]. The correlations between the factors to determine the degree to which the factors were distinct from one another were examined. Final acceptance or rejection of the models was based in part on conventional statistical criteria for a good fit model but was also based on the magnitude and significance of the standardized factor loadings and how well the model made sense from a theoretical perspective[25,38].

To assess the internal consistency of the CD-RISC-25 and CD-RISC-10, Cronbach's alphas were calculated for the overall score as well as the proposed sub-scales (factors) emerging from the EFA and assessed their level of acceptability accordingly ($\alpha \geq 0.9$ excellent, $0.9 > \alpha \geq 0.8$ good, $0.8 > \alpha \geq 0.7$ acceptable, $0.7 > \alpha \geq 0.6$ questionable, $0.6 > \alpha \geq 0.5$ poor, $0.5 > \alpha$ unacceptable)[39]. The construct validity of the CD-RISC-25 and CD-RISC-10 was assessed by calculating Pearson correlations among the two measures' overall resilience scores and factors emerging from their respective factor analysis with the multi-attribute scale and emotion single attribute sub-scale of the HUI3 and all six sub-scales of the PWB. The strength of the correlations is reported using the following criteria: 0.90-1.00 very high; 0.70-0.90 high, 0.50-.70 moderate, 0.30-0.50 low, and 0.00-0.30 negligible[40].

4.4. Results

The sociodemographic and disease characteristics of participants (those with complete CD-RISC-25 questionnaires: n=322, 89.9%) and those excluded from analysis (incomplete CD-RISC-25 questionnaires: n=36, 10.1%) are presented in Table 4.1. Given the small number of non-completers, the precision of a multivariable logistic regression analysis would be poor, so crude differences between groups are reported. Completers were more likely to be younger, working, have more years of education and shorter disease duration since symptom onset. There were no other statistically significant differences between completers and non-completers.

4.4.1. Exploratory Factor Analysis

In the random split of the sample, there were 168 cases in Sample 1 for the EFA and 154 cases in Sample 2 for the CFA. For the CD-RISC-25 EFA, the Bartlett's test of sphericity showed that there were patterned relationships between the items (χ^2=2295.74, p≤0.001). The KMO measure was 0.92 indicating the data were sufficient for EFA. Using an eigenvalue cut-off of 1.0, a five-factor structure emerged, explaining a cumulative variance of 54.49%. Table 4.2 shows the factor loadings after rotation using the significance criterion of >0.32. In reviewing the items that composed the five different factors, the factors were labelled according to the themes they presented: *positive acceptance of change* (seven items), *personal competence* (seven), *secure in oneself and others* (five), *perseverance* (four), and *spiritual influences* (two).

The CD-RISC-10 EFA, tested as a fixed factor model containing only one factor, demonstrated patterned relationships between the items (χ^2=790.36, p≤0.001) and had a similar KMO measure at 0.90. This one-factor model resulted in a cumulative variance of 47.24%. In keeping with the nomenclature used for this one-factor model of the CD-RISC-10, this factor was similarly termed resilience (Table 4.3).

4.4.2. Confirmatory Factor Analysis

Using Sample 2 (n=154), a CFA model was first estimated using the five factors that emerged during the CD-RISC-25 EFA (Figure 4.2). This model resulted in the following goodness of fit statistics: χ^2(df=255) = 434.30, p<0.001; SRMR = 0.07, RMSEA = 0.07, CFI = 0.90. All CD-RISC-25 items had significant standardized factor loadings (Figure 4.2) ranging from 0.41 (question 2) to 0.91 (question 9), all with p values <0.01. However, there were very high correlations (0.78-0.96) among four of the five factors in the model, indicating the factors may not be completely distinct from one another. The exception was the fifth factor, *spiritual influences*, which had low correlations with the other four factors, ranging from 0.23-0.31. The CD-RISC-10 one-factor model resulted in the following goodness of fit statistics: χ^2(df=35) = 63.15, p=0.002; RMSEA = 0.07, CFI = 0.96, SRMR = 0.05 (Figure 4.3). The ten items had significant factor loadings, ranging from 0.41 (question 6) to 0.82 (question 16).

Table 4.1. Sample Characteristics for Completers (N=322) and Non-completers (N=36) of the CD-RISC-25

Characteristic		Completers (n=322) n (%)	Non-completers (n=36) n (%)
Sex: n (%)	Male	56 (21.5)	4 (14.3)
	Female	205 (78.5)	24 (85.7)
Age: Mean (SD†) *		**47.51 (11.75)**	**54.52 (9.86)**
	Marital Status: n (%)	65 (25.1)	7 (24.1)
	Single/Divorced/Widowed Married/Partner	194 (74.9)	22 (75.9)
Education Status: n (%)*	**High School or Below**	**92 (25.9)**	**16 (35.6)**
	Post-Secondary	**263 (74.1)**	**29 (64.4)**
Employment Status: n (%)*	**Working/Employable**	**147 (55.9)**	**11 (37.9)**
	Not Working Due to MS	**116 (44.1)**	**18 (62.1)**
Relapse in past 2 years: n (%)	No	73 (28.1)	12 (42.9)
	Yes	187 (71.9)	16 (57.1)
Disease Course: n (%)	Relapsing-remitting	153 (61.7)	17 (58.6)
	Primary/Secondary Progressive	95 (38.3)	12 (41.4)
Comorbid Condition: n (%)	No	118 (48.8)	13 (65.0)
	Yes	124 (51.2)	7 (35.0)
Duration of Disease since Onset:* Mean years (SD)		**19.98 (11.72)**	**25.50 (11.03)**
Patient Determined Disease Steps: Mean (SD)		2.71 (2.40)	3.04 (2.38)
HOPE Agency (goal directed energy) Score: Mean (SD)		24.58 (5.15)	23.89 (5.85)
HOPE Pathways (planning to meet goals) Score: Mean (SD)		24.83 (4.78)	24.76 (4.92)
HUI3 Emotion Sub-Scale Score: Mean (SD)		0.91 (0.18)	0.90 (0.20)
HUI3 Multi-attribute Score Mean (SD)		0.59 (0.30)	0.51 (0.27)
PWB Autonomy Score: Mean (SD)		13.71 (2.56)	13.47 (3.04)
PWB Environmental Mastery: Mean (SD)		13.46 (3.19)	14.32 (3.35)
PWB Personal Growth : Mean (SD)		15.26 (2.76)	15.00 (3.28)
PWB Personal Relationships: Mean (SD)		11.09 (1.75)	11.40 (2.24)
PWB Purpose in Life: Mean (SD)		13.67 (2.98)	14.06 (4.16)
PWB Self-Acceptance: Mean (SD)		13.61 (3.48)	13.88 (3.59)
CD-RISC-25 Overall Score Mean (SD)		72.17 (14.47)	74.40 (16.63)‡
CD-RISC-10 Overall Score: Mean (SD)		29.09 (6.37)	29.44 (7.22)‡

*Statistically significant differences ($p<0.05$) between completers and non-completers are in bold print.

†Abbreviations: SD = standard deviation; HUI = Health Utilities Mark Index 3; PWB = Psychological Well-Being; CD-RISC = Connor- Davidson Resilience Scale

‡CD-RISC scores for non-completers were derived using imputation of missing items

Table 4.2. Exploratory Factor Analysis from Sample 1 (N=164) for CD-RISC-25

Positive Acceptance of Change		**1**	**2**	**3**	**4**	**5**
1	I am able to adapt when changes occur	0.661				
4	I can deal with whatever comes my way	0.547				
5	Past successes give me confidence in dealing with new challenges and difficulties	0.661				
6	I try to see the humorous side of things when I am faced with problems	0.581				
7	Having to cope with stress can make me stronger	0.801				
8	I tend to bounce back after illness, injury or other hardships	0.604				
14	Under pressure, I stay focused and think clearly	0.487				
Personal Competence						
15	I prefer to take the lead in solving problems rather than letting others make all the decisions		0.563			
17	I think of myself as a strong person when dealing with life's challenges and difficulties		0.457			
18	I can make unpopular or difficult decisions that affect other people, if it is necessary		0.725			
20	In dealing with life's problems, sometimes you have to act on a hunch without knowing why		0.624			0.332
23	I like challenges		0.549			
24	I work to attain my goals no matter what roadblocks I encounter along the way		0.461			
25	I take pride in my achievements		0.566			
Secure in Oneself & Others						
2	I have at least one close and secure relationship that helps me when I am stressed			0.632		
13	During times of stress/crisis, I know where to turn for help			0.769		
19	I am able to handle unpleasant or painful feelings like sadness, fear and anger			0.615		
21	I have a strong sense of purpose in life			0.607		
22	I feel in control of my life			0.543		
Perseverance						
10	I give my best effort no matter what the outcome may be				0.473	
11	I believe I can achieve my goals, even if there are obstacles	0.385			0.610	
12	Even when things look hopeless, I don't give up				1.012	
16	I am not easily discouraged by failure				0.368	
Spiritual Influences						
3	When there are no clear solutions to my problems, sometimes fate or God can help					0.659
9	Good or bad, I believe that most things happen for a reason					0.641
	Eigenvalues	10.462	1.768	1.384	1.232	1.063
	% of Variance	40.153	5.167	3.512	3.030	2.628

Table 4.3. Exploratory Factor Analysis from Sample 1 (N=164) for CD-RISC-10

	CD-RISC-25 Question	Factor
1	I am able to adapt when changes occur	0.674
4	I can deal with whatever comes my way	0.802
6	I try to see the humorous side of things when I am faced with problems	0.506
7	Having to cope with stress can make me stronger	0.638
8	I tend to bounce back after illness, injury or other hardships	0.611
11	I believe I can achieve my goals, even if there are obstacles	0.773
14	Under pressure, I stay focused and think clearly	0.745
16	I am not easily discouraged by failure	0.651
17	I think of myself as a strong person when dealing with life's challenges and difficulties	0.783
19	I am able to handle unpleasant or painful feelings like sadness, fear and anger	0.634
	Eigenvalues	4.724
	% of Variance	47.235

Figure 4.2. – Confirmatory Factor Analysis Diagram of CD-RISC-25

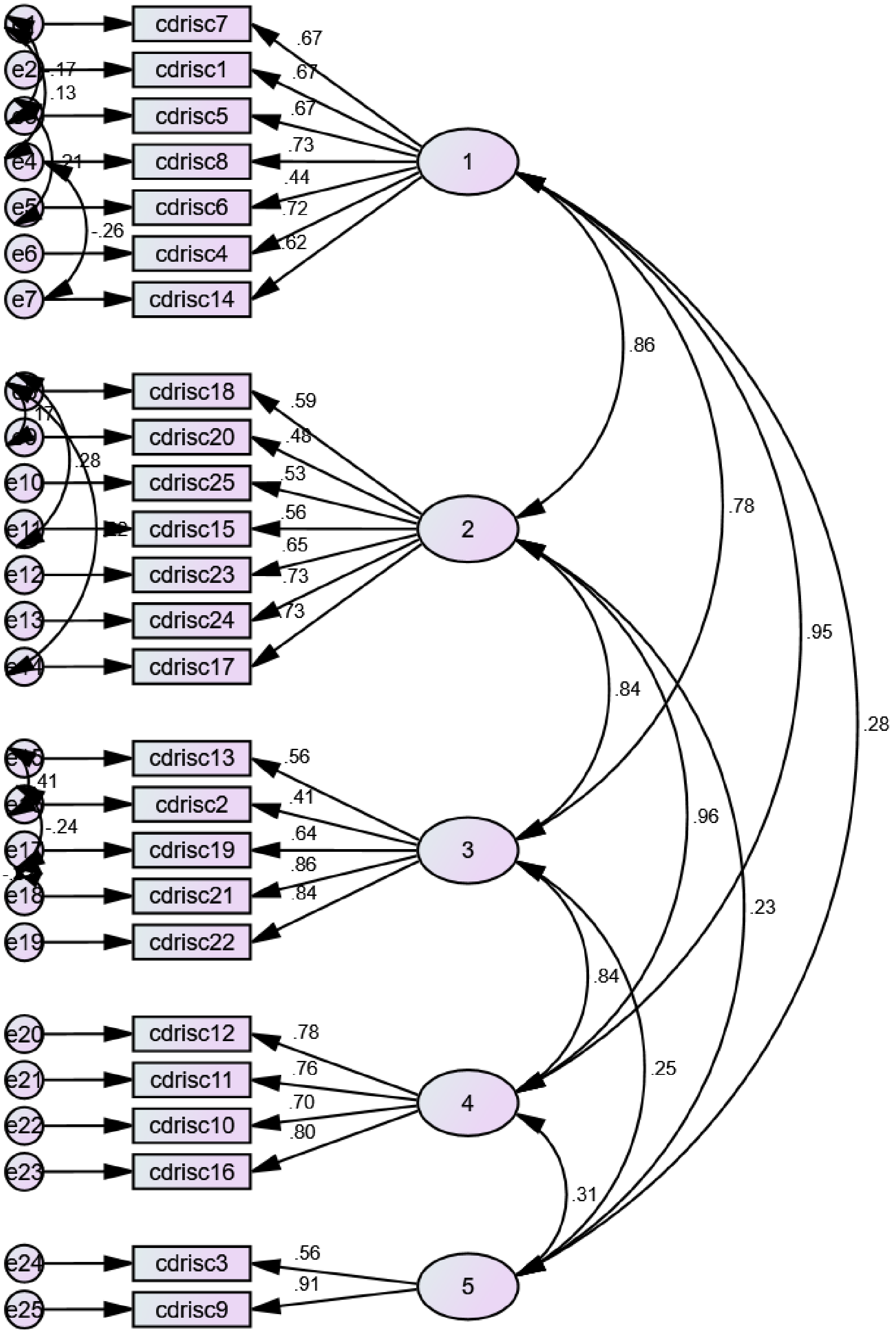
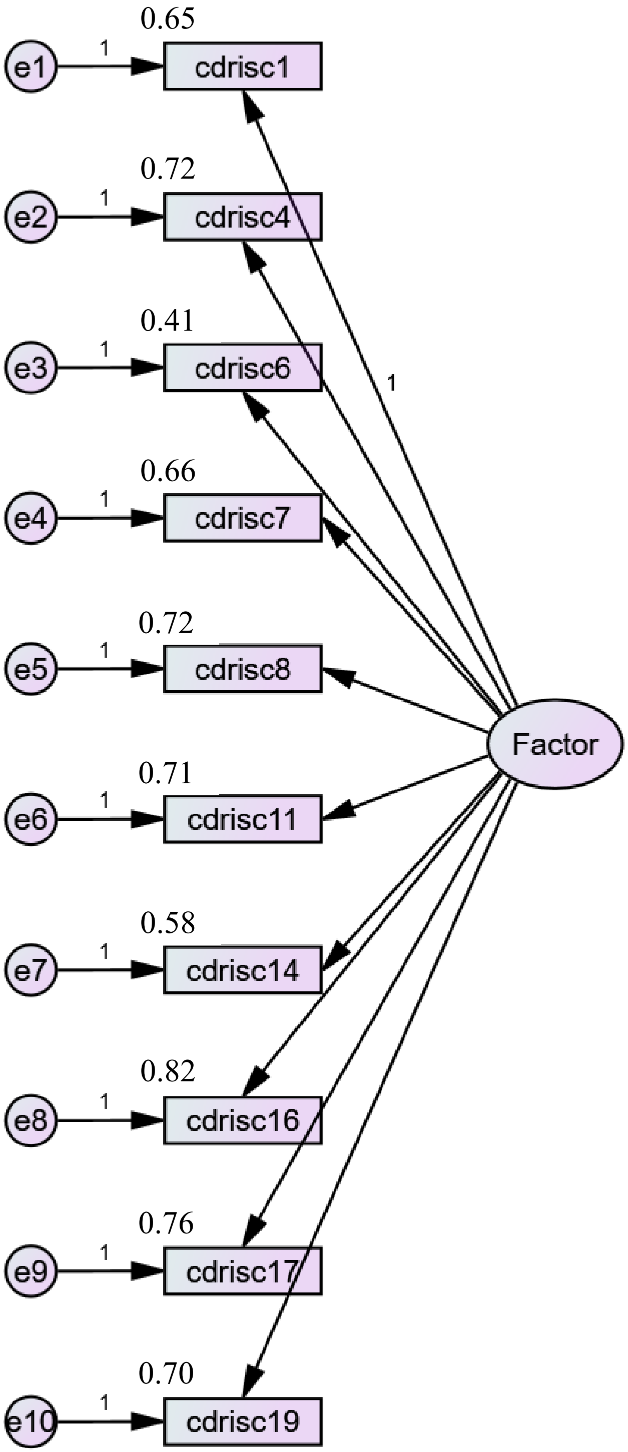


Figure 4.3. – Confirmatory Factor Analysis Diagram of CD-RISC-10



4.4.3. Reliability and Construct Validity

The Cronbach's alpha values for the CD-RISC-25 and CD-RISC-10 total scores were excellent at 0.93 (95%CI: 0.92, 0.94) and 0.89 (95%CI: 0.87, 0.91) respectively. The first four factors emerging from the CD-RISC-25 EFA had good Cronbach's alpha values: *positive acceptance of change* α=0.84 (95%CI: 0.82, 0.87), *personal competence* α=0.84 (95%CI: 0.81, 0.86), *secure in oneself and others* α=0.82 (95% CI: 0.79, 0.85), *perseverance* α=0.82 (95%CI: 0.79, 0.85). The Cronbach alpha for the fifth factor, *spiritual influences,* was lower at 0.68 (95% CI: 0.60, 0.74).

The correlation matrix used to test construct validity is reported in Table 4.4. For the first four factors and both overall resilience scores, higher/better resilience scores were positively correlated with higher/better HRQL and PWB scores, though none of the correlations were strong or very strong. The strongest correlations were found with the PWB environmental mastery, personal growth and self-acceptance sub-scales, achieving moderate level correlations with the resilience scores and first four factors. Correlations with the PWB autonomy, personal relationships and purpose in life were low to moderate. Correlations with the HUI3 emotional sub-scale score were low to moderate, but with the HUI3 multi-attribute score, only low correlations emerged. The correlations were negligible for the fifth factor, spiritual influences.

Table 4.4. – Pearson Correlation Coefficients (95% Confidence Intervals) Between CD-RISC-25, CD-RISC-10, 5 EFA Factors and Health Utilities Index (HUI3) Multi-attribute Score, Emotion Sub-Scale, and Psychological Well Being (PWB) Sub-Scales

Scale†	CD-RISC-25	CD-RISC-10	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
HUI3 Emot	0.56* (0.41-0.69)	0.50* (0.33-0.62)	0.47* (0.30-0.60)	0.38* (0.21-0.54)	0.69* (0.55-0.79)	0.51* (0.35-0.65)	0.13 (-0.05-0.31)
HUI3 Multi	0.39* (0.22-0.54)	0.36* (0.18-0.50)	0.40* (0.23-0.54)	0.27* (0.10-0.44)	0.43* (0.18-0.50)	0.33* (0.16-0.49)	0.02 (-0.16-0.20)
PWB AU	0.47* (0.33-0.61)	0.45* (0.31-0.59)	0.43* (0.28-0.56)	0.56* (0.43-0.70)	0.32* (0.31-0.59)	0.43* (0.28-0.57)	0.03 (-0.13-0.19)
PWB EM	0.66* (0.53-0.77)	0.63* (0.49-0.74)	0.59* (0.45-.71)	0.55* (0.42-0.69)	0.67* (0.49-0.74)	0.58* (0.44-0.70)	0.12 (-0.04-0.28)
PWB PG	0.67* (0.54-0.78)	0.62* (0.48-0.73)	0.63* (0.50-0.74)	0.59* (0.45-0.72)	0.64* (0.48-0.73)	0.57* (0.44-0.70)	0.09 (-0.07-0.25)
PWB PR	0.55* (0.41-0.68)	0.47* (0.32-0.60)	0.44* (0.28-0.57)	0.45* (0.30-0.59)	0.62* (0.32-0.60)	0.46* (0.31-0.60)	0.13 (-0.03-0.30)
PWB PL	0.56* (0.31-0.60)	0.45* (0.30-0.58)	0.46* (0.31-0.59)	0.41* (0.27-0.56)	0.46* (0.30-0.58)	0.41* (0.25-0.55)	-0.05 (-0.22-0.11)
PWB SA	0.63* (0.50-0.75)	0.57* (0.43-0.69)	0.53* (0.38-0.64)	0.56* (0.42-0.69)	0.66* (0.43-0.69)	0.53* (0.39-0.66)	0.15 (-0.01-0.32)

Yellow = 0.50-0.70 Moderate; Blue = 0.30-0.50 Low; White = 0.00-0.30 Negligible

*Correlation is significant at the 0.01 level (2-tailed).

†CD-RISC=Connor-Davidson Resilience Scale (25-item and 10-item); HUI3 Emot = Health Utilities Index Mark 3 (HUI3) Emotion Sub-scale; HUI3 Multi = HUI3 Multi-attribute scale; PWB AU = Psychological Well-being (PWB) Autonomy Sub-scale; PWB EM = PWB Environmental Mastery Sub-scale; PWB PG = PWB Personal Growth Sub-scale; PWB PR = PWB Personal Relationships Sub-scale; PWB PL = PWB Purpose in Life Sub-scale; PWB SA = PWB self-acceptance

4.5. Discussion

The primary aim of this study was to explore the factor structure of both the CD-RISC-25 and CD-RISC-10 amongst persons with MS using EFA and CFA and compare the model fit between the two. Five factors emerged from the CD-RISC-25 EFA, and one factor emerged from the CD-RISC-10 EFA. The CFA goodness of fit statistics for the CD-RISC-25 five-factor model were fairly good but did fall shy of the conventional statistical criteria for a good fit model[25]. In particular the RMSEA was greater than 0.06 at 0.07, and the CFI was less than 0.95 at 0.90. The CD-RISC-10 unidimensional factor model performed better, especially with regard to the RMSEA at 0.07 and CFI at 0.96. While these results indicate the CD-RISC-10 one-factor model may be better, it is important to keep in mind the developers of the CD-RISC-25 intended it to provide a single score of resilience measurement. An investigation into a one-factor model with the CD-RISC-25 may have resulted in goodness of fit statistics similar to the CD-RISC-10 one-factor model. However, since the goal was to explore how many factors might emerge from the EFA, a pre-set number of factors to be extracted was not set in the analysis software program.

As stated earlier, both versions have strong psychometric properties for measuring resilience as a single construct[10,12,14]. The choice of whether to use the CD-RISC-25 or the CD-RISC-10 when measuring resilience in persons with MS will depend upon such factors as the research question(s) at hand and respondent questionnaire burden. While the goodness of fit model statistics suggests the five factors should not be used as sub-scale measurements of resilience, the five factors give us insight into what the underlying constructs may be for resilience in the MS population, specifically: *positive acceptance of change, personal competence, secure in* *oneself and others, perseverance and spiritual influences*. We could apply this information toward designing resilience strengthening interventions for persons with MS.

The factor that emerged with the highest Eigen value and percentage of variance explained in this sample was *positive acceptance of change* (questions 1, 4-8, 14). Interestingly, half of the CD-RISC-10 items (1, 4, 6, 7, 8) overlapped with this top factor. Acceptance has been defined as the act of taking or receiving something offered; favourable reception; the act of assenting or believing[41]. Positive acceptance of change was the third factor described in the original US population EFA of the CD-RISC-25. Questions 1, 4, 5 and 8 also composed this factor in the original factor analysis. The fact that positive acceptance of change had the highest Eigen value and percentage of variance explained is particularly salient because of the ability for this factor to be modified, as results from pilot studies suggest. For example, a stress management and resilience training (SMART) program in breast cancer survivors resulted in improvements in resilience and overall quality of life[18]. A group therapy approach addressing resilience in patients with depression and/or anxiety led to significant improvements[6]. A recent pilot project of a resilience training program conducted in Australia with persons with MS demonstrated positive outcomes upon resilience, quality of life, depression and stress[19]. Through the use of cognitive-behavioural therapies, in particular Acceptance and Commitment Therapy (ACT), the participants in the above studies were able to increase their ability to positively accept change which thereby increased their resilience.

The second strongest factor in this sample was termed *personal competence* (questions 15-18, 20, 23-25) due to the nature of the questions (solve problems on own, make difficult decisions, work to attain goals, take pride). The third factor was termed as *secure in oneself and* *others* (questions 2, 13, 19, 21-22), again due to the nature of the questions (have close relationships, know where to turn for help, able to handle unpleasant or painful feelings, have a sense of purpose of life, feel in control). The fourth factor was termed *perseverance* (questions 10-12, 16) (give best effort, believe one can achieve goals, not give up, not be easily discouraged). These three factors of personal competence, secure in oneself and others, and perseverance, have aspects that relate to other factors found to be associated with resilience including positive affect (positive emotions and expressions) and self-efficacy (perceived ability to overcome the challenges associated with MS)[1]. They are also similar in nature to qualitative study findings regarding MS persons' perspectives on facilitators of resilience which included psychological adaptation, social connection, life meaning and planning[56]. Perseverance was one of the descriptors persons with MS used to describe successful psychological adaptation to MS[56].

From a theoretical perspective, the five factors identified in this study resonate with the literature regarding how persons with MS can live well with their chronic illness. For example, the concept of acceptance is associated with better quality of life, positive relationships and positive adjustment in persons with MS[42-47]. The five factors, *positive acceptance of change, personal competence, secure in oneself and others, perseverance and spiritual influences,* could serve as the basis for the generation of resilience strengthening interventions for persons with MS. One study found in the literature pointed to the potential success of resilience enhancing interventions. It was a pilot study of a 6-week positive psychology program titled *Everyday Matters* developed by the National MS Society (US). The researchers found the program to have positive impacts on resilience, satisfaction with social roles, positive affect and well-being, and depressive symptom severity. That program covered topics such as how to train one's brain to focus on the positive, how to limit one's focus to small manageable goals to achieve more, and how to build one's social support network[20].

The internal consistency of both versions of the resilience scale was high, and there was evidence of construct validity through positive correlations among scores on the resilience scales and other constructs (HRQL and PWB) that are theoretically related to psychological resilience[2,26,27,43]. However, at most the correlations were moderate in strength, and many correlations were low. As there are many ways to measure construct validity, additional research using other methods such as discriminant validity will help to accumulate evidence for assessing the construct validity of these resilience instruments in the MS population.

The first four factors emerging from the EFA in this study had good internal consistency and low to moderate construct validity, but the fifth factor (*spiritual influences*) did not. The CD-RISC-10 excludes questions 3 and 9, the two questions composing the fifth factor of spiritual influences in this study. The authors of the CD-RISC-10 stated that the reason these two questions did not remain in their final EFA and CFA of the CD-RISC-25 was statistical. The authors speculated that, if more questions in the CD-RISC-25 had addressed spiritual influences, this factor may have emerged as a reliable and valid construct of resilience, because generally factors should contain three to five items[14].

Existing literature supports a relationship between spiritual influences and better coping with chronic diseases[48,49]. For example, positive spiritual coping (use of faith for comfort or strength to deal with difficult circumstances) has been found to be associated with less internalization of problems and better health[50]. Research in this area in MS is emerging. Positive spiritual coping was found to be associated with noticing and appreciating the positive aspects of life, regardless of symptoms and severity of the disease[51]. Spiritual growth was positively correlated with participation in life roles and health-related quality of life[52]. Preliminary work suggests spirituality may indeed facilitate resilience whether or not patients formally adhere to a specific religion or belief[53-55]. The term spirituality can be defined in many ways. Further research is perhaps warranted to discover the various ways in which persons with MS may define spirituality. Understanding the definitions would help in the understanding of how spiritual factors may be related to resilience.

There were limitations to this study. The participants were volunteers. As such, it is possible only those who were interested in the concept of resilience and/or who felt they were "resilient" may have participated. Perhaps different results would emerge in the EFA and CFA in persons who feel they are not resilient. Due to the study inclusion criteria the study findings may not generalize to youth with MS, those recently diagnosed with MS, the cognitively impaired or the severely disabled. Furthermore, as mentioned previously, not all 358 of the participants completed the CD-RISC-25 in its entirety. Differences between completers and non-completers raise the possibility of response bias by age, employment status, education level, and disease duration in this study. The availability of the survey to be completed online may have been more appealing to those potential participants who were younger, working and had more years of education. Their comfort and trust level with providing information online may have been higher compared to older persons and those who were no longer working and had fewer years of education. However, since the number of non-completers was small (10%), the differences between groups were modest, and there were no significant differences in disability level or in scores on the questionnaires administered, response bias is unlikely to have had an important impact on the study findings.

4.6. Conclusions

The results from this study facilitate our understanding of the construct of resilience among persons living with MS. The findings suggest that the CD-RISC-25 and CD-RISC-10 are reliable and valid measures of resilience in the MS population and that both versions can be used in this population. It is noteworthy that positive acceptance of change was one of the most prominent resilience factors. The other emerging factors can be conceptualized as personal competence, being secure in oneself and others, perseverance and spiritual influences. If this factor structure can be replicated in other studies with persons with MS, the resulting confidence in the critical constructs could guide the development of resilience-based interventions.

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CHAPTER 5

Manuscript Title: Experiential Descriptions of Four Components of Resilience: Adapting to MS, Coping with MS, Social Support and Wellness

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CHAPTER 5: Experiential Descriptions of Four Components of Resilience: Adapting to MS, Coping with MS, Social Support and Wellness (Study 3)

5.1. Chapter Synopsis

Background: Multiple sclerosis (MS) is a chronic disease of the central nervous system, often characterized as a progressive, variable and uncertain illness. These characteristics can make adjusting to and coping with this illness very difficult, often resulting in poor physical, mental and social outcomes including depression and low quality of life. Within the context of chronic diseases, psychological resilience has been defined as the process of overcoming adversity and is the balance of two important aspects, resources and vulnerabilities, both of which include personal and environmental facets. In MS, research has found resources to include psychological adaptation, problem-focused coping strategies, acceptance of one's situation, and setting and pursuing goals. Vulnerabilities include physical symptoms such as disability, fatigue, pain, visual disturbances and cognitive dysfunction, as well as psychological symptoms such as depression and anxiety. The work to date regarding resilience resources and vulnerabilities in MS has mainly stemmed from quantitative inquiry. Developing an understanding of resilience in persons with MS requires a knowledge of the factors that comprise resilience resources and vulnerabilities and an understanding of how those with MS experience and describe these resources and vulnerabilities. The former has been accomplished through both qualitative and quantitative work, while the latter is best accomplished using qualitative research strategies. ***Purpose:*** To expand upon the current literature related to resilience in MS, the purpose of this study was to use qualitative methods to explore how persons with MS describe their experiences of specific components of resilience. ***Methods***: Convenience sampling was used to recruit a

subsample of participants from the larger survey study that examined factors associated with resilience in those with MS. Twelve participants agreed to take part in semi-structured interviews about four specific components of resilience: adapting to MS, coping with MS, social support and wellness. These four components were chosen based on previous research regarding their importance in resilience in MS. The tape-recorded interviews were transcribed verbatim and analyzed using a qualitative description approach. This approach allows the researchers to work closely with the data to provide a description and summary of the findings as the participants communicated them. ***Results:*** The participants described adapting to MS as changing self-expectations, living differently, navigating roles and responsibilities, and adjusting to continually changing abilities. They described coping with MS as acceptance, perspective, knowledge seeking, denial and faith. Social support was described as leaning on others, strained connections, community, sustaining distance and seeking expertise. Wellness was described as managing symptoms and finding a path. ***Conclusions:*** The participants' responses reflected a mix of both positive and negative experiences. In the MS literature, these components are often referenced in positive terms only as resilience resources. The reality is that for many, these "resources" also have aspects of difficulties or challenges. The findings from this qualitative study: (i) expand the body of knowledge on how those with MS adapt to and cope with MS, (ii) point out the beneficial and not so beneficial roles played by family, friends and employers of those with MS, and (iii) provide a glimpse into how those with MS experience wellness. This information can be used to inform further research questions, such as how to strengthen resilience among persons with MS and what impact those efforts will have.

5.2. Introduction

Multiple sclerosis (MS) is one of the leading causes of non-traumatic neurological disability in young adults[1]. As a chronic disease of the central nervous system, the symptoms of MS can include vision problems, tingling and numbness, pain and spasms, weakness, gait and ambulation difficulties, balance problems or dizziness, cognitive dysfunction, bladder issues and fatigue[2]. For the majority of persons with MS, the initial phase of their disease is characterized by appearance of new or exacerbated symptoms, followed by periods of relative recovery, known as relapsing-remitting MS[3]. Recovery from relapses in the early stages often appears complete, however most relapses leave behind some damage to the nervous system. As neurological damage accumulates, recovery from relapses becomes less complete. Development of disability progression, independent of relapses, results in sustained disability for many with relapsing-remitting MS. This change in disease course is known as secondary progressive MS[3]. For a smaller portion of persons with MS, 5-15%, gradual accumulation of disability begins from the outset, known as primary progressive MS[3].

Common features amongst all types of MS include the variability between and within persons as to the type, degree and frequency of symptoms they experience throughout their disease course as well as the uncertainty surrounding the level of disability they will reach[4]. The combination of the progressive, variable and uncertain nature of MS can make adjusting to and coping with this illness very difficult[5, 6]. Depression is common among those with MS[7,8], and many of the physical and psychosocial symptoms of MS are associated with poorer quality of life[9-12]. Although advances in MS treatments, such as disease-modifying therapies, have a beneficial impact on the progression of the disease, it is still often psychologically and socially overwhelming and debilitating for those living with it[13,14].

Within the context of chronic diseases such as MS, psychological resilience has been defined as the process of overcoming adversity and is the balance of two important aspects, resources and vulnerabilities, both of which include personal and environmental facets[15,16]. In MS specifically, resources include such aspects as learning to psychologically adapt, taking a problem-solving approach to coping, accepting one's situation and pursuing personal goals[17-22]. MS symptoms such as progressive disability, fatigue, pain, visual disturbances, cognitive dysfunction, and mental health problems such as depression, anxiety and stress, are some of the vulnerabilities[9,23-25]. In MS, higher levels of resilience are associated with social and mental health factors including satisfaction with social support, less depression and anxiety, and better quality of life[22,26]. Interventions designed to strengthen resilience in those with MS have provided initial evidence that improving resilience leads to improvements in psychosocial outcomes such as quality of life, depression and social roles[27,28].

The work to date regarding resilience resources and vulnerabilities in MS has mainly stemmed from quantitative inquiry. However, one qualitative study on resilience and MS has explored what participants' believed were the facilitators and barriers to resilience[29]. Psychological adaptation and coping, social connection, life meaning, planning, and physical wellness were considered facilitators, while resilience depletion (burn out), negative thoughts and feelings, social barriers, stigma, and physical fatigue were considered barriers[29]. These facilitators and barriers were described by participants, but their experiences with them were not explored. In addition, two qualitative studies investigating what those with MS perceive to be part of healthy aging in MS have found that resilience is seen as important[30, 31]. Resilience, along with financial flexibility, mental and cognitive health and social support, were cited as being a foundational factor of healthy aging[30]. In that study, participants considered resilience to include: (i) adapting to changes and disease symptoms, (ii) seeking out and gaining new knowledge, (iii) pursuing self-therapy, (iv) dealing with uncertainty, (v) resolving problems on one's own, and (vi) coping with and overcoming barriers[30]. In the second qualitative study on healthy aging, resilience was described by the participants as emotional mastery, avoidance of negative chronic mood states, and the ability to adapt to new circumstances[31]. Adaptation was further described as shifting or restructuring goals, an inevitable and important part of aging well, and a process that developed over time[31].

It is very useful to know what those with MS believe resilience to be and what characteristics they describe as comprising resilience resources and vulnerabilities. However, this is only part of the story. In order to fully understand these resources and vulnerabilities, it is important to know how these resources and vulnerabilities are experienced by those with MS. Understanding the described experience with these aspects of resilience is an important step in identifying ways to foster and sustain resilience in those living with MS. Thus, to expand upon the current resilience in MS literature, the purpose of this study was to explore, using qualitative methods, how persons with MS describe their experiences of some of the components of resilience identified in the two qualitative studies outlined above[29,30]. Specifically, the components of resilience of interest in this study were: adapting, coping, social support and wellness.

5.3. Methods

5.3.1. Study Design

A qualitative description approach was taken to address the aim of this study. This method allows the researchers to work closely with the data as presented to provide a description and summary of the findings as the participants communicated them[32]. This type of approach works well when the purpose of a study is to uncover the words and phrases persons use to describe the event or concept being studied[32].

5.3.2. Participant Recruitment

Convenience sampling was used to recruit participants from those participants who participated in the larger survey study that examined factors associated with resilience in those with MS (Paper 1)[21]. Briefly, participants for that larger study were recruited from four MS specialty clinics in Western Canada and through the MS Society of Canada's print and e-newsletters. Inclusion criteria for the larger study were: (1) age ≥18 years, (2) English-speaking, (3) self-report of a confirmed diagnosis of MS by an MS specialist, (4) self-reported confirmation of having MS for at least two years, since symptom onset, and (5) self-reported ability to complete the questionnaire independently. At the end of the survey, participants indicated their willingness to be contacted about future studies by the research team, including taking part in an interview about resilience. Those expressing willingness were directed to a separate website which collected their name and contact information. For those participants who completed the survey via paper and pencil, a separate postage-paid envelope was included allowing them to mail their name and contact information to the research team separately from the anonymous survey. For practical purposes, the list of potentially interested participants was limited to those living in the same city as the interviewer.

While the aim of quantitative sampling is generalization to the larger population under study, the aim of qualitative sampling is to gain an in-depth understanding the phenomenon of interest. Therefore qualitative sample sizes are much smaller than quantitative[33]. The number of participants required to understand a phenomenon depends on a number of factors, including the qualitative method being used and data saturation (i.e., when no new data emerge and there are sufficient data to articulate an understanding of the phenomenon[33,34]). As it was unknown at the start of the interviews how many participants would be required to obtain data saturation, 20 potential participants were mailed an information letter that directed them to contact the research team directly to schedule an interview. Of these, twelve agreed to be interviewed. Additional participants could have been recruited if data saturation was not achieved, but that turned out to be unnecessary. Ethics approval was obtained from the University of Alberta Health Research Ethics Board (Appendix A), and all participants provided signed informed consent (see information letter and consent form in Appendix D).

5.3.3. Participant Characteristics

The sociodemographic and clinic characteristics of this sample, abstracted from the cross-sectional survey (see Paper 1), are presented in Table 5.1. The median disability level was 5.0 on the Patient Determined Disease Steps (PDDS) reflecting advanced disability *("Late Cane: To be able to walk 25 feet, I have a cane, crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances"*[35]). The most common comorbidity was depression with 50% indicating they either currently had depression or had depression at some point in their past. The average Hospital Anxiety and Depression Scales (HADS) scores reflected mild levels. Most of the sample had moderate fatigue, as measured by the Daily Fatigue Impact Scale (D-FIS), and moderate stress scores, as measured by the Brief Inventory of Perceived Stress (BIPS). The average overall score on the Multidimensional Scale of Perceived Social Support (MSPPS) scale indicated the participants mildly to strongly agreed they had supportive significant others, family and friends. The average score on the Health Utilities Index Mark3 (HUI3) 0.3 fell into the severe disability category, reflecting a low overall health-related quality of life.

In comparison to the descriptive characteristics of the source population, these twelve interview participants had a more equal percentage of females and males, slightly lower percentage of post-secondary education, higher percentage of not working due to MS, more progressive types of MS, and fewer relapses. They did not differ on marital status or on age. With a median PDDS score of 5.0, they were more disabled than the source population (median = 2.0). An increase of 1.0 on the PDDS has been identified as indicative of disease progression[36,37]). At 0.3, the HRQL scores in the sample comprising the current study were lower than the HRQL scores of the source population at 0.6 (a difference of 0.3 on the HUI3 has been identified as the minimal clinically important difference[38]). The sample in the current study also had slightly lower fatigue and resilience scores, although these differences may not be clinically important. Anxiety, depression, stress and social support scores were very similar.

Table 5.1. Sample Characteristics of Qualitative Study Participants and Cross-Sectional Study Sample (Source Population for Qualitative Participants)

Characteristic	Qualitative Sample (n, %)‡	Source Population† (n, %)‡
Sex		
Female	7 (58.3)	229 (79.2)
Male	5 (41.7)	60 (20.8)
Marital Status		
Married	9 (75.0)	216 (75.0)
Single/Divorced/Widowed	3 (25.0)	72 (25.0)
Education Status		
High School or Below	5 (41.7)	108 (37.0)
Post-Secondary	7 (58.3)	184 (63.0)
Employment Status		
Working	3 (25.0)	158 (54.1)
Not Working Due to MS	9 (75.0)	134 (45.9)
Clinical Course		
Relapsing-Remitting	4 (33.3)	170 (61.4)
Primary or Secondary Progressive	8 (66.7)	107 (38.6)
Relapse in Past 24 Months		
Yes	4 (33.3)	203 (70.5)
No	8 (66.7)	85 (29.5)
At Least 1 Comorbid Condition		
Yes	7 (58.3)	131 (50.0)
No	5 (41.7)	131 (50.0)
Characteristic	**Mean (range)‡**	**Mean (range)‡**
Age (in Years)	47.2 (11.1; 25.0-61.0)	48.2 (11.7; 21.0-77.0)
Clinical Measures*		
Disease Duration Since Symptom Onset	22.4 (12.9; 4.0-46.0)	20.5 (11.7; 2.0-57.0)
Disability Level (PDDS)	4.8 (2.7; 1.0-8.0)	2.7 (2.4; 0.0-8.0)
HRQL (HUI3)	0.3 (0.3; 0.0-0.6)	0.6 (0.3; -0.3-1.0)
Fatigue (D-FIS)	15.4 (5.7; 5.0-24.0)	12.5 (7.6;0.0-32.0)
Anxiety (HADS-A)	10.2 (2.7; 6.0-14.0)	10.0 (2.5; 5.0-16.0)
Depression (HADS-D)	8.4 (1.6; 6.0-11.0)	8.4 (1.6; 4.0-13.0)
Stress (BIPS)	26.5 (21.1-39.0)	26.3 (7.0; 9.0-45.0)
Social Support (MSPSS)	63.2 (13.9; 38.0-83.0)	65.0 (16.3; 12.0-84.0)
Resilience (CD-RISC)	68.2 (16.9; 47.0-100.0)	72.4 (14.7; 23.0-100.0)

*PDDS=Patient Determine Disease Steps; HUI3=Health Utilities Index Mark 3; D-FIS=Daily Fatigue Impact Scale; HADS-A=Hospital Anxiety and Depression Scale-Anxiety; HADS-D=Hospital Anxiety and Depression Scale-Depression; BIPS=Brief Inventory of Perceived Stress; MSPSS=Multidimensional Scale of Perceived Social Support; CD-RISC=Connor Davidson Resilience Scale; †Source population=participant characteristics from Table 3.3 (Study 1); ‡SD refers to standard deviation; range refers to range in the study sample; % refers to valid percent

5.3.4. Data Collection and Analysis

Data were collected from May through December of 2015 using semi-structured, individual interviews (Interview guide can be found in Appendix F). Interview items focused on four key components of resilience: adapting to MS, coping with MS, social support, and wellness. These components were chosen *a priori* based on review of quantitative and qualitative studies reporting key elements associated with resilience in those with MS[21,27-30,39]. The interview questions were constructed to elicit descriptions of experiences that may help operationalize how these components of resilience present in the day-to-day lives of persons with MS. The number of resilience components being explored was small in order to minimize respondent burden and the length of interviews. Everyday language was used, and participants responded using their own understanding of these terms rather than being given clinical or scientific definitions of the terms. Balanced questions were used to facilitate participants' willingness to respond both positively and negatively. All interviews were conducted by the author of this thesis.

After providing written informed consent and consent to audio record the interview, participants were informed at the beginning of the interview that they were free to take a break, decline to answer a question, stop the interview at any time, or withdraw from the study. If participants wanted to spend more time on a question, they could do so without pressure to proceed to the next question. Consent to continue was periodically re-confirmed during the interview to ensure the participants felt comfortable with the time it was taking to complete the interview as well as the questions themselves.

The interviews were transcribed verbatim and analyzed using a directed content analysis approach[40]. This type of analysis is appropriate for qualitative description design as it allows for description and summary of the data as they were presented[41]. The goal of direct content analysis is to group the large amounts of narrative text across and within interviews into the categories of similar meanings (in this case, categories reflecting adapting, coping, social support, and wellness) to provide knowledge and understanding of how these concepts are defined and described by participants. The analysis process begins by examining the factors queried in the interviews yet allows for new or unanticipated categories to emerge based on the responses of the participants[40,41]. Themes and sub-themes were developed through an iterative process of reviewing and re-reviewing the data. The data were organized and re-organized to ensure all intricacies of each theme and sub-theme were appropriately and thoroughly captured. Of the 20 potential participants invited to take part in the study, twelve agreed to be interviewed. Recurring themes emerged from these twelve interviews, suggesting saturation and therefore no need to recruit additional participants.

The trustworthiness of this study was evaluated using the criteria proposed by Lincoln and Guba in their fundamental 1985 work on assessment of rigor in qualitative research: credibility, transferability, dependability, and confirmability[33,72]. They define *credibility* as "whether the findings make sense and if they are an accurate representation of the participants and or data", *transferability* as "applicability of the findings (being transferred) to other settings", *dependability* as "the post hoc opportunity to review how decisions were made through the research", and *confirmability* as "used during the data collection and analysis phase to ensure the findings are reflective and logical"[72]. Confirmability and dependability may be assessed through the use of an audit trail of the documented researcher's decisions. Transferability may be assessed by describing the research setting and participant characteristics, and credibility may be assessed through strategies such as prolonged engagement in and triangulation of the data[33,72]. The iterative process taken to construct themes and sub-themes from reviewing the data was completed from a prolonged engagement with the interview transcripts by the primary author of this study and supported by two researchers with expertise in qualitative inquiry (credibility, dependability). Each draft was saved with comments and notations describing the changes made and rationale for each, essentially providing an audit trail of the analyses (dependability, confirmability). The final iteration was reviewed by two MS neurologists to ensure the findings read as logical and to assess for congruence with their clinical experience (credibility, confirmability). The descriptive characteristics of the twelve participants were reported and compared to the source population characteristics (Table 5.1). The implications of the differences are presented in the discussion section of this chapter (transferability).

5.3.5. Reporting of Findings

Findings are reported in the four main themes reflecting each of the resilience components comprising the interview guide. Subthemes arising from the data in each category are reported and described with labels that characterize the content of the subtheme. At the end of the findings of each of the main categories, exemplar quotes are cited. Participants are identified by number, and the number of the participant providing each quote is in brackets at the end of the quote.

5.4. RESULTS

All participants completed the interviews that generally lasted between 90 and 120 minutes. Two asked that the interview be paused but continued after a five-minute break. None of the participants withdrew from the study or asked that the interview be stopped. The following themes conceptualize how persons with MS describe their experiences of adapting to MS, coping with MS, social support, and wellness. While these sections are reported as if they were distinct, there is considerable overlap. The themes also point to the myriad of complex ways individuals experience living with MS. Exemplar interview quotes for each section are included in Tables 5.2 – 5.5.

5.4.1. Adapting to MS

Overall, participants described adapting to MS as figuring out how to live with a body and a mind they could no longer trust to function as it should. When the participants experienced their body or mind not functioning as it ought, they were prompted to find solutions to prepare for and compensate for the failings of their body and mind. They did not know when, where or how their body and mind would fail, they just knew that it would. Adapting to MS became a necessity for the participants. It was not a choice. Their choices became how they were going to change and adjust. The participants described adapting to MS as changing self-expectations, living differently, navigating roles and responsibilities, and adjusting to continually changing abilities.

5.4.1.1. As Changing Self-expectations

Adapting to the challenges that came with MS involved many changes for the participants, including what they could expect from themselves. They often commented that they had to make both major and minor alterations in their self-expectations because of their new level of physical abilities and that they were no longer able to do their work, chores, errands, and hobbies as quickly or in the same manner as they had previously. They reported having to allot more time to tasks and spread the tasks out over time, such as cutting the grass in small sections over several days or grocery shopping more often since they could manage only a little bit at a time. Activities of daily life, such as showering, were no longer done without thought as to the amount of energy that would be required to complete such tasks considering the all the other tasks that had to be completed that day. For example, taking a shower could be all that was perceived as accomplishable. Indeed, the participants indicated they often had to “lower their standards” when it came to how much they could realistically expect themselves to do. Housework, for example, had to be done less and less frequently, as the ability to keep up with it became more and more difficult. In this way, there were temporal dimensions to adaptation as a change in self-expectations.

The participants also talked about changes in the types of expectations they now had of themselves. There was an increase in how closely they needed to pay attention to their bodies’ signals and how much they had to pre-plan their day to day activities and social outings. The participants did not have the luxury of being able to hold their bladder nor decide in the moment to stay on the dance floor. They were now confronted with bodily expectations, something they had not previously had to think about or think through. There were consequences to inattention and pushing oneself beyond what had been planned, such as embarrassing incontinence and severe fatigue. The participants learned they had to be intentional about what activities they were going to do, when they would start and stop, and how they were going to accomplish their activities. They had to find a new rhythm to their life.

5.4.1.2. As Living Differently

For the participants, adaptation was described as finding a new rhythm that required figuring out how to incorporate therapies, medications and aids into daily life. Time and space often had to be created in the participants' lives for MS medications. The participants remarked that, though they knew they needed to take the medications and were generally thankful for the medications, it was not always easy. Prednisone, for example, a common treatment for managing acute symptoms, was talked about as being "the worst" because of the side effects such as not being able to sleep. Many of the medications for managing the symptoms of MS and disease-modifying medications (controlling the disease itself) had side-effects. Intravenous medications required blocks of time away from home and work, and injectable medications required an ability and willingness to self-inject.

Accepting that new ways had to be found for ambulation was a common adaptation that most participants were initially resistant to, namely using equipment such as canes, walkers and wheelchairs. However, once they started using the needed equipment, they commented they found great reprieve from exhaustion and were grateful to have made the transition. Other seemingly simple adaptations, such as Velcro straps on shoes, ice picks on walking sticks and bigger handles on cooking utensils, were also very helpful.

Bladder frequency and urgency were particularly salient problems for most of the participants and necessitated new ways of doing things (e.g., self-catheterization). Participants faced questions such as, "what if there is only one toilet stall available and it is occupied when I need it?” “What will people think if I use the wheelchair accessible bathroom even though I am not in a wheelchair, nor am using a cane or walker, but can’t stand and wait in a long line?” The reality of these issues meant protective measures often needed to be taken to avoid embarrassing accidents, including choosing to not drink anything at an activity, wearing bladder leakage underwear or learning to self-catheterize. The alternative, not leaving the house, was not practical nor did the participants see that as a long-term solution.

Just as living differently required adding things to one’s life, such as medications, walkers, and catheters, it also required subtracting to a certain degree. For example, some of the participants spoke of giving up driving and handing certain tasks over to others. Creativity was also often required to live differently, such as using one’s left hand to start the car and put it in gear, because the right arm had gone completely numb. Life carried on for the participants and their families, so the participants had to figure out how they were going to carry on given the demands MS imposed upon their time, energy, and abilities.

5.4.1.3. As Navigating Roles and Responsibilities

For some of the participants, adaptation was described as involving a change in roles and responsibilities. This seemed especially striking for the male participants who often reflected that their wives had to take on the outdoor chores that they themselves used to perform, such as cutting grass and shoveling snow. This change was difficult to adapt to, as was the fact that they could no longer do everything they used to do. They had to either give up doing the chores they once did entirely, or they had to accept help from others to complete them. Most of the male participants further commented that their MS necessitated their wives now working outside of the home fulltime, since they themselves could no longer work at all or had to reduce their hours.

For some of the men, this meant taking on the household chores, such as cooking and cleaning, that their wives had previously been responsible for; while for others, it meant having their spouse now working in addition to doing household chores, because the men simply were not able to do much to help around the house.

The female participants also talked about navigating their roles and responsibilities, particularly regarding taking care of their children. They had to find ways to keep feeding, driving and being with their children while facing many physical obstacles. Often, they had to let family members take on some of the caregiving activities. They sometimes made decisions to not do certain things such as enrolling children in extracurricular activities, as they simply did not have the energy required to get their children to these activities. The female participants expressed mixed emotions over these types of decisions, as they wanted their children to have opportunities but also wanted to be as healthy as possible for their family, thus difficult decisions had to be made.

Many participants reported changes and adjustments related to their work role. As mentioned above, most participants described stopping working earlier than they had originally planned, taking early retirement or going on disability pension. Therefore, they were faced with the challenge of being retired or on disability pension much early than they thought they would be and had to adapt to a life without the structure and social connection that comes with working. Sometimes they had to change the type of work they were doing because of their MS. For example, one participant became a teacher instead of a mechanic to lessen the physical demands on his body. Sometimes the participants would have liked to continue working in some capacity but finding a job that would fit with their symptoms was difficult. For example, one participant was physically able and willing to do most of the work required to be a clerk in a clothing store (e.g., placing clothes on racks, greeting customers) but was unable to work the cash register due to cognitive issues. Since the job required cash register work, she was let go from the job, despite her employer's acknowledgement that she was friendly and a hard worker. The participant commented how hard this was for her, in view of the fact that employment programs are available for people with other disabilities such as developmental disabilities; yet she was unaware of any similar programs available for those with MS.

Cognitive difficulties often meant that working was not feasible due to employers' demands. Many were willing and able to work for a few hours every day without unduly taxing their cognitive reserves but stated that, in their experience, most employers wanted workers for two or three full days in the workweek. Working full days was not an option for the majority of the participants. Thus, even part-time work was not possible.

5.4.1.4. As Adjusting to Continually Changing Abilities

The participants remarked that adjustments were continually needed. They would adapt to a decrease in their level of ability, for example working part-time instead of full time, and would be able to sustain that level of adaptation for a period of time. Inevitably though the participants indicated that level of ability would also eventually decrease, resulting in further adaptations such as stopping work and going on long term disability. The rate at which adaptations were required as the disease changed and progressed seemed "to pick up speed", as commented by many of the participants. For example, one participant found he was able to walk unassisted for seven years before needing a cane, so he expected he would be able to use the cane for seven years before needing a walker and the walker for another seven years before needing a wheelchair. However, for this individual, the intervals between the changes in level of assistance got shorter and shorter with each progressive change. For many of the participants, the shorter timeframes between changes meant their concerns over how the disease would progressively impact them over time changed from thinking in terms of months and years to weeks and even days of “what’s next?” and trepidations over what further adaptions lay ahead as their disease continued to progress. At any point in time, the impact of the disease was incomplete, and there would be a continuous need to change and adjust.

The participants reported certain events as being particularly dramatic for them in terms of the degree of adjustment that was required. These events included when they received the diagnosis, stopped work, quit driving, or needed more support for ambulation (ambulatory to cane, cane to walker, walker to wheelchair, or home to long term care centre). As they passed through these trying milestones, they had to adjust to living in a way that was different from what they had anticipated. Each of these changes was momentous for the participants and reminded them that they were dealing with an uncertain, variable and progressive illness that required ongoing adaptation. Given the constantly changing and progressing nature of the disease, adapting to MS was a dynamic process for the participants.

Table 5.2. Participants' Verbatim Interview Responses – Adapting to MS

As changing self-expectations	So you get out the Weed Eater… You know, because I can do a certain amount of time and then I need to rest. (Participant 04) Because sometimes you do kind of feel sorry for yourself… I'll wipe out and fall on something. Or spill a glass of tomato juice on the rug, and just go, oh, I hate this. Or I've gone to the bathroom in my pants, and I've got to take a shower. I'm just like nobody should have to live like this. But for the most part, I'm okay. I talk to myself. The [rehabilitation program for MS patients] taught me to sort of be a little more patient with myself and to forgive myself for not being able to do stuff… (Participant 09) Sure, adjustments have to be made. Like I have to plan ahead. Okay, if I'm going to go here, then I've got to plan it's going to take this much time, and I'm going to need this much…I need my walker, I need a walking stick or whatever. And don't over-do it. Because you feel bad for the rest of the day and maybe the next day even. And yet you want to have a life so you've got to balance that out. (Participant 12)
As living differently	So for years, 7 years, I didn't go see [the MS specialist]. I got pretty severe double vision, and then that scared me. So I dragged myself back talk to the MS specialist. I said I think I'm going to have to start using an MS medication. I feel okay about that. I feel like I'm fighting back. (Participant 02) I think now I need to look into, as much as I really hate to because it's just pride, but getting a walker. Walking with a cane is even a big deal, but if I don't, I'll be misconstrued as a drunk or whatever. (Participant 10)
As navigating roles and responsibilities	I mean there's probably 5 or 6 times where I took my sons with me to the emergency room. But I would make it like an adventure…we'd see these drunks falling off chairs or just slurring and talking away. And the boys found it entertaining. (Participant 05) I cut my work back to 3 days a week because it was hard to, you know, like to do everything…So I was allowed to go part-time. And that worked for quite a while until it was just way too much…The hardest thing is when you stop, you leave that whole culture, friends, baseball tournaments, wine and cheese, Christmas parties. When you stop, all of that stops. (Participant 08)
As adjusting to continually changing abilities	Walking was just becoming more and more difficult. I walked with a cane for a few years. And then I had a walker. And I only walked with the walker for just a year and then it was the wheelchair after that, and I've been in the wheelchair ever since. It slowly started going and then picked up speed. (Participant 03) We're thinking if we do end up staying here [house] and I can't do the stairs anymore, we may have to put a bed down here in the dining room. And this will become my bedroom. I'd be okay with that. (Participant 09)

5.4.2. Coping with MS

For participants, coping with MS involved figuring out how to live with MS without letting the MS diagnosis and prognosis overwhelm them. The participants all discussed times when they felt they were coping well and times when they felt they were not. Coping was described as a mix of both effective and ineffective strategies, as well as positive and negative thoughts and feelings, with the aim being to find ways for the positive to outweigh the negative.

5.4.2.1. As Acceptance

Participants described coping as an acceptance of one's self and one's situation. Many participants reflected that, with time, they came to terms with having MS, finding life activities that were within their control. For example, in an attempt to "beat the MS", several participants spoke of taking up exercise and trying to eat better when they were first diagnosed. However, all the participants found that, despite their best physical efforts, the disease progressed, and new or worse symptoms appeared. Acceptance became "doing the best I can" with the limitations they had. For some, acceptance also meant reflecting on those aspects they were happy about in their lives and those aspects that brought them meaning. For example, one participant resumed painting, an activity she had enjoyed in the past but did not have the time to do while she was working. No longer being able to work freed up hours during the day for her to do this activity that brought her contentment. Another participant reflected how thankful she was that her MS had resulted in an early retirement, because that gave her precious time with her grandchildren.

Acceptance was also communicated by the participants in their willingness to let go of plans and goals they had previously envisioned and to set new plans and goals that realistically aligned with their current and anticipated abilities. In many cases, the participants talked about simplifying their goals and re-ordering their priorities. What they had once thought was important, for example work and possessions, became less so while maintenance of health and meaningful relationships became more important.

The participants further explained their experience of coping as acceptance by framing their struggles affirmatively. For example, participants described being able to find humour even in the troubles of tripping, limping, and falling. Participants described how such humour would put the people around them who observed the fall or the limp more at ease and how it helped their own spirits to laugh at themselves. Viewing the disease of MS as something their body was doing “to hurt itself”, versus something they were doing or not doing on purpose to cause the MS, also appeared to provide the participants with a helpful way to frame their disease.

5.4.2.2. As Perspective

Quite often the participants would cope by comparing their situation with that of others. These comparisons seemed to provide the participants with a different perspective on the reality of their experience of living with a chronic disease. The participants acknowledged the difficulties having MS meant for their lives, describing MS as an “ugly disease” or saying that “MS sucks”, while simultaneously acknowledging that a lot of conditions are difficult. Cancer was a common comparison, and participants cited the difficulties persons with cancer have in potentially facing death due to their disease which is generally not the case for persons with MS. Additionally, they commonly compared their own disabilities with other disabilities caused by other conditions such as those caused by spinal cord injuries and strokes. Participants viewed the sudden onset of disability inflicted by these causes as potentially more traumatic to cope with than the gradual decline of MS.

Indeed, some of the participants reflected the perspective that the progressive course of MS gave them the benefit of time to think through future scenarios and options, enabling them to perhaps be somewhat more prepared for what may come. Several of the participants also remarked that MS had enhanced their compassion for others in general. They often commented that a person may not know what the neighbour, the co-worker, the grocery clerk or the fellow patient in the waiting room is struggling with in their life. They expressed how having a disease that is characterized by both visible and invisible symptoms increased their empathy for others.

5.4.2.3. As Knowledge Seeking

Coping with MS meant taking the time and making the effort to learn about MS. The participants spoke of doing their own reading and research as well as reaching out to MS health care providers and organizations such as the MS Society. Learning about MS, “doing a deep dive “and “arming oneself with information”, was a necessity for many of the participants, because what they knew initially about MS was limited. They expected, to a certain degree, to have sensory symptoms such as numbness and motor symptoms such as weakness, but symptoms such as incontinence and cognitive dysfunction often came as a surprise. Several of the participants talked about people they had known growing up who had MS, including family members and friends. While knowing someone who had MS provided a reference point for their understanding of MS and what it may involve, the participants usually found out quite quickly that their experience with MS was a unique experience. Thus, drawing direct comparisons between themselves and others wasn’t going to provide all the answers they needed.

However, the participants did find talking to others with MS helpful for widening their knowledge base. Beneficial ideas on how best to manage symptoms, navigate the health care system, and seek out medical and alternative therapies arose from talking with others with MS. The participants re-iterated that, despite many similarities, each person's personal and medical circumstances combined to form a unique experience with MS. This meant they had to figure out for themselves what pieces of information were relevant and helpful to their own experience of MS and to discard those pieces of information that weren't. While assisted by learning from others, coping through knowledge seeking was generally an individual exercise marked by continuous reading and research.

5.4.2.4. As Denial

Denial was sometimes used as a way to cope, especially in the early years, mostly just after diagnosis, perhaps to give them some time to come terms with the fact they had MS. Several participants indicated they were not actually told "you have MS" in those exact words. Therefore, even though they knew that they had MS because of the test results from the MRI findings and lumbar punctures and the medications they were being put on, at least initially, they carried on as though they did not have it because the specialists did not use those exact words. However, in all cases, the words "you have multiple sclerosis" were eventually used. The participants commented that having this time of denial was helpful in living with MS without having their feelings overwhelm them. It was a way of slowly adjusting their mindset to the fact they now had an incurable disease with an uncertain future. However, the participants also commented on the necessity of moving on from denial towards acknowledgement and acceptance of their MS.

Denial was talked about as a temporary way of dealing with the diagnosis rather than a long-term strategy.

5.4.2.5. As Faith

Faith in God provided some participants a framework for working through the thoughts and feelings associated with MS. Their faith provided those participants with a resource outside of themselves from which to draw strength. Strength was described in terms of believing God is in control of their past, present, and future, and therefore, God will provide the internal and external resources they need to face the physical and psychosocial challenges and complexities associated with having MS. The participants also expressed belief in there being a purpose or reason for why they had MS. Several of the participants talked about their view that having MS evoked empathy for others and ignited a desire to give back to others in some way. They also expressed the importance of not losing faith, because faith provided hope.

Others spoke of relying on their own inner strength – a faith in themselves as being more than their disease. They used self-acknowledgement phrases such as “illness is not you, you are you”, “I’ve got MS, but MS does not have me”, “Someone will always be better off than you, and someone will always be worse than you”, and “MS is not me”. Participants often described the difficulties they were facing as transient with faith that tomorrow would be better.

The participants also reflected on faith in medical advances. They expressed high interest in MS research regarding treatments. Though the pace of research was slower than they would have liked, and disappointments were frequent (“works in mice but not humans”), they believed that strides were being made in the number and quality of treatments available. They expressed appreciation about their physicians’ attendance at conferences to learn about the latest treatments. This faith in medical advances was sometimes viewed as potentially benefiting future persons diagnosed with MS rather than themselves. In fact, a frequent idea expressed was faith that those diagnosed with MS in the future will have a much different experience, most likely a more positive one, because of the changing treatment landscape.

Table 5.3. Participants’ Verbatim Interview Responses – Coping with MS

As acceptance	But whatever, you have it, you deal with it. What other choice do you have? And you do the best that you can for yourself, you know. So you rest because you’re too fatigued. You know, you exercise because you want to keep those muscles working, right. And you do things where you get to laugh too.” (Participant 08) I have a pretty good sense of humour. So usually I just joke around about it [falling] easily now. I’ll just say, oops, I shouldn't have had vodka in my orange juice this morning, or whatever. (Participant 10) It's just a matter of living day-to-day and being happy with where you are and who you know. You have to keep on going because it’s something that you never expected. It's something that’s part of mother nature. That sometimes she’s cruel to some people and sometimes she’s not. So it’s something that you can’t really deny but still you have to accept. (Participant 11)
As perspective	You hear about people with other diseases that are so much worse – cancer, AIDS, even people with MS that are so much worse. And you think, oh, how selfish of me to even feel sorry for myself sometimes, you know. (Participant 09) You go to the [rehabilitation hospital], and you see people there missing limbs, that have had strokes. And then there's me there, and I can do everything that’s in front of me. And you get a new perspective and say how good I have it…Because for those guys, bang, their life has changed just like that. (Participant 12)
As knowledge seeking	I just devoured everything. I’d read whatever I could on everything. (Participant 05) I have learned so much from the people at my [MS Society] group. You know what, I didn’t even know, [name of friend] is on a medication for balance. And I’m like there’s a medication for balance? So I’m going to talking to my doctor about that. I learn a lot. I wish I had done it sooner. (Participant 09)
As denial	I spent a few years really in denial. And I think that’s what kept me away from the clinic, right. And I otherwise felt fine, you know. So yeah, if I just ignore it maybe it will go away. But it didn’t, right. (Participant 02) And you know, what I thought… I mean denial is the best... even though my husband and I were sitting there and he was telling us, you know, you have lesions… I’d always blame it on Taekwondo because that was better than actually thinking that, you know, I had MS. So I totally denied the fact that there would be any chance. Because he said I probably had it. He didn’t say I did, right? (Participant 10)
As faith	I have really strong faith because I can’t do it on my own. I know not everybody is religious but it really does make a difference. (Participant 01) Maybe tomorrow will be better, you know. And so far… It might be like a metaphorical tomorrow. It might be next week or whatever. But so far, it always has. There always has been a tomorrow that has been better. (Participant 03)

5.4.3. Social Support

Overall, participants described social support as connections and contacts with family, friends, co-workers, support groups and MS health care specialists. While the participants expressed tremendous appreciation for the support they received, they also reflected that misunderstandings, expectations and structures could impede how that support was received and incorporated. Social support was described by the participants as leaning on others, although at times they experienced strained connections. They also highlighted the importance of both maintaining community connections juxtaposed with a need to sustain some emotional distance. Also key was seeking help from those with MS expertise.

5.4.3.1. As Leaning on Others

The participants frequently referred to the practical help they received from family and friends. Most of the participants could manage basic self-care activities, such as grooming, dressing and feeding, but needed help with activities beyond this scope, such as household chores, grocery shopping, and getting to appointments. If they did need assistance with everyday tasks or unanticipated challenges, family members were usually turned to rather than friends, due to the personal nature of the support being required. Participants sometimes also needed financial assistance, and again, family members tended to be called upon more than friends. However, neighbours and the general public also provided unsolicited and helpful responses when they saw participants struggling with taking out the garbage or carrying a food tray in a fast food restaurant.

Participants often talked about feeling guilty, awkward or badly that they required help. They recognized that in some cases the help they required was personal and embarrassing for both parties and in some cases was physically demanding for the helper. Thus, leaning on others was difficult and required a clear acknowledgement that they were not able to manage by themselves. Even though family, friends, co-workers and even strangers were often very willing to help, accepting that help was hard to bear. While the MS diagnosis served as an explanation for individuals' needs for support and for their behaviour as being socially acceptable, participants still wanted to be in control of how they received help. They wanted to sustain semblances of the character of their relationships as spouse, parent, sibling, friend, and so forth.

5.4.3.2. As Strained Connections

Despite the general willingness of others to be helpful, the experience of social support was complex: dependency and freedom, guilt and absolution, obligation and responsibility, expectations and excuses, relief and disappointment. Family was described as being especially supportive and understanding at key times such as diagnosis, beginning a particular therapy or becoming wheelchair bound. In contrast, it was harder for families to sustain support and understanding when having to take more responsibility for day-to-day life events such as cleaning, cooking and laundry. Participants talked of being called “lazy”, “drama queen”, and “damaged” by family members. These words were hurtful, and participants talked about being misunderstood since they saw themselves as wanting, but being unable, to do everything their family thought they should be able to do.

5.4.3.3. As Community

The participants stressed the importance of having connections in the community. They recognized that community needs differ depending on individual's life circumstances but felt that it is necessary to talk with others, as internalizing all the various thoughts and emotions was not healthy. It sometimes took courage to connect with others and wasn't always easy to go out in public with a disability. Being with people was a deliberate, and not always easy, choice. The participants generally found others with MS to be important sources of support and usually connected to others with MS through support groups. However, this experience was variable in how helpful it was.

For some, support groups were very helpful in providing a safe space to talk about issues since other group members would understand without detailed explanations. These groups were as helpful for information and support. Sometimes though, the common problems faced by group members caused the focus to be negative rather than problem solving and sharing solutions. A few of the participants also talked about how it can be frightening at first to attend support groups because others in the group had substantial disabilities that forced them to face their own probable future. However, attending support groups over time seemed to increase participants' comfort, and the benefits of attending, such as being with others who understood their own struggles and feeling validated, tended to outweigh the fears.

Involvement in other types of social groups also provided support. For example, coffee groups, music groups, theatre community and exercise classes provided support that was not MS-specific. This was viewed as "normal support" as an outlet for talking about life and a sense of belonging in the world apart from the MS.

5.4.3.4. As Sustaining Distance

At the same time, participants described sometimes avoiding intimacy, keeping secrets, or otherwise sustaining distances from others. Knowing that they were going to need ongoing support from family and friends, participants talked about avoiding sharing too much. For some, this was to decrease the risk of alienating others and risk losing that support. For example, the participants did not want to divulge too much information about their bladder and bowel issues, because “no one wants to talk about that”. Too much sharing was also seen as burdening and worrying their family and friends.

And yet in sustaining relational distance, participants expressed concern for others, looking for opportunities to care for others, help others, or otherwise give back to family, friends, and their community. Concern for others afforded opportunities for the participants to look beyond their own struggles to find ways to listen and support others even if only for short intervals of time. Children, including sons, daughters, nephews, nieces and grandchildren, were often described by participants as helping the participants focus on other aspects of life, because the children often made them laugh, feel better, and needed.

5.4.3.5. As Seeking Expertise

Support to navigate the uncertainty and variability of MS also required help beyond family and friends. The participants mentioned MS health care providers and patient organizations such as the MS Society, as being particularly pivotal sources of support. They expressed a need for health care providers with whom they could be completely open and honest about every symptom and who understand the complexities of MS at the biological, clinical and personal level. They talked about their gratitude for opportunities to see their MS neurologists, nurses and other health care professionals such as psychologists and orthotists and found complementary therapists such as massage therapists and dieticians to be important resources.

The MS Society was frequently referenced by the participants as being a tremendous resource. The variety of programs, services and equipment was held in high regard and was viewed as critical to helping the participants navigate the complexities of MS and the health care system. The MS Society was particularly helpful in navigating government income programs for the disabled and facilitating connections with other patient advocacy organizations, health care stores, and community resources.

The participants also mentioned some of the challenges they encountered with the health care system. One problem was lack of access at times when it was most needed. For example, one patient remembered having optic neuritis during the holiday period and experiencing long delays in getting treatment because the hospital staff and labs were not working at full capacity. Practical concerns such as the cost of parking and distance of the parking lots from their doctors' offices were often cited as issues. However, other practical aspects of their medical care, such as having a lab, pharmacy and doctor's office in one building, were especially appreciated and made their lives easier.

Table 5.4. Participants' Verbatim Interview Responses – Social Support

As leaning on others	When I was first diagnosed, I did feel alone. I was going through this. But you know, it just takes opening your eyes a little bit to notice that friends were around you and family. And so it really didn't last for very long. I don't feel alone. (Participant 03) Like when I had a nurse come to the house to show me how to inject myself with this [MS medication], my older son took notes for me. He said, "I'm going to write notes, what she tells you. So if you forget, you know I'll have it written down." Then… my younger son, sat with me while I did my injection. I was scared to be by myself. (Participant 05) I felt kind of bad because it was hot and you've got somebody that has to push you [in a wheelchair]. And then a couple of times I tried pushing it myself. But then my arms would get tired and then I would be exhausted. And [participant's husband] said, "The whole point of the wheelchair is that you're not exhausted." So I said, okay, fine. (Participant 07)
As strained connections	My sister, she's like "Well, this [MS] explains it. I used to think you were lazy. I didn't understand. Now it makes sense. All the naps, your energy level, your pain, your weird things, it makes sense." (Participant 06) The problem was I told friends and family I had MS, and then people would say to me, "You can't do that." Like we're not going for walks anymore because you can't do that. You can't go shopping all day, you just can't do that. It took them quite a long time to realize that I still wanted to do stuff. (Participant 07)
As community	So the MS Society, when I went to that, that I thought was a good day because you finally get a bunch of people that have the same thing, and you're talking about the same thing. "Yeah, that happens to me," or that's like that. (Participant 04) It's good to have friends who have MS, because bad days happen to them as well, right. As much as my family loves me, they don't really know, right. The only know what they can see and I tell them. (Participant 08)
As sustaining distance	The chair lift was something I waited too long to get because I didn't tell anybody I had been falling. I didn't want to worry my husband because he stresses out and then he doesn't sleep. (Participant 07) There's a lot that I don't necessarily tell everybody. Because it doesn't really affect anything and do they really need to know all of those things? No. They don't have to have that burden or that worry, you know. Because I don't want them to have that worry. (Participant 08)
As seeking expertise	Be really blunt and really honest with those doctors. If you aren't, they can't help you. And a lot of people just expect them to. No matter how disgusting or how embarrassing it is, you just… They can't help you if you're not. (Participant 01) So I cried out. I went to the MS Society. (Participant 04)

5.4.4. Wellness

In general, the participants described experiences of feeling unwell rather than experiencing wellness. Their experiences tended to highlight that wellness was something they wanted but struggled to achieve. The participants described wellness in terms of having to manage physical and psychological symptoms but also as finding a path towards wellness.

5.4.4.1. As Having to Manage Symptoms

Participants described wellness in terms of managing of physical and mental/psychological symptoms. The most troublesome physical symptoms discussed by participants were visual disturbances, fatigue, pain, cognitive difficulties, urinary incontinence, and ambulation difficulties. The experiences of optic neuritis were especially poignant, with participants stating emphatically they “never wanted to have that again”. The “invisible” symptoms, including fatigue and cognitive dysfunction, were difficult to tell others about, to make them understand, when others would reply “I’m tired too” or “I forget stuff too.” This was frustrating for participants who struggled with finding the words to describe how their fatigue was different and more than just being tired. Worry about urinary incontinence consumed much of the participants’ thoughts and time. One participant recalled thinking for a very long time that her problem with incontinence was apparent to others until she finally realized that there was “not some sign around her neck announcing this to the world”. Her occupation with the issue was only in her head, and everyone else was too occupied in their own heads to be thinking “I wonder if she has to go to the bathroom?” Incontinence was a substantial concern, however, and some spoke of not wanting to get to the point where they had to wear a diaper.

The participants found the very visible symptom of walking difficulties a constant concern. In some ways, this symptom was easier to explain to others than the invisible symptoms such as fatigue, because others could readily see the difficulties the participants were experiencing and thus tended to immediately understand how difficult it must be for the participants. However, it still often created embarrassment for the participants and sometimes misunderstanding. Several participants recalled times when they had been mistaken for being drunk because of their inability to walk in a straight line or without stumbling. Of all the physical symptoms the participants had to manage, gradual decline in ambulation was the most often cited physical worry in regards what level of care may be needed in the future.

Depression was frequently mentioned by the participants. They relayed stories of others wondering why they could not “just be happy” or “bounce back”. These feelings of depression often occurred in conjunction with a major MS-related event such as diagnosis or stopping work. Sometimes, however, it was hard for the participants to distinguish depression from fatigue, as fatigue was so common. It helped to have someone to talk to in order to manage their mood, as otherwise negative thoughts and feelings tended to take a “foothold”.

5.4.4.2. As Finding a Path

Like most adults, the participants had dreams and aspirations, plans and goals they wanted to achieve. Wellness meant coming to terms with the fact these dreams and goals may need to be altered or perhaps even abandoned. Indeed, this was a struggle for many of the participants. Their life trajectory was now on a different path, which often came with a sense of loss. The losses the participants experienced were eventually named as such, loss of pride and loss of dreams. The participants had to find a “new normal”, had to “re-write the script”. The reality they were living was often different from the one they had planned, and the participants realized the importance of accepting this fact and letting go of their pride and their plans.

The participants related several examples of times when there seemed to be so many questions with no answers. The participants acknowledged that they would have “highs and lows”, “peaks and valleys”, and that the future was likely to continue to bring new challenges, including the possibility of having to move into an assisted living or long-term care facility. While this possibility of having to be cared for was not particularly appealing to the participants, they reflected the need to be realistic about what their future may entail.

The participants talked about “glimmers” and “moments” of wellness. Glimmers were found in playing music, getting a hug from a nephew, laughing at a joke. The participants also commented that they had a lot more to be hopeful about than many years ago. Treatments for MS are now available, and government, health care, and community programs and services help participants maintain independence and function for longer than in previous decades. The participants were able to “hope for the best but plan for the worst”, an idiom the participants commented may not have been the reality in the past for persons with MS. Even planning for the worst may not have been possible, as less knowledge and understanding of the disease was available to patients, so planning for the future was filled with even more uncertainty than today. While the participants usually did not consider themselves to be healthy, they did have a sense of wellness in their willingness to keep looking to the future with hope.

Table 5.5. Participants’ Verbatim Interview Responses – Wellness	
As having to manage symptoms	I got that diplopia [double vision], and that kind of really scared me. Vision problems. I didn’t want to go back. I remembered the optic neuritis. I didn’t want to go back to that, right. (Participant 02) Well, I’ve only finally been able to sort of bounce back a bit probably within the last 9-10 months now… the past couple of years pretty much depression, and just, yeah, staying at home doing nothing, like nothing day in and day out. (Participant 10) I really needn’t concern myself with really being over-dramatic about the invisible things, you know, my legs feel like I have pins poking me all over. But it’s more the outward disability, my right leg and the foot drop. Sometimes I wish if I knew it would probably get worse, I would like totally cut my leg off. A prosthetic would be easier. (Participant 10) I was walking with a limp [at work]. And my limp kept getting worse. And I was stumbling a bit. It was like I was drunk. And everyone asked me, “what’s with you? I came [into the cafeteria], stumbled, hit the table, and knocked all the food off the table and on all these guys. So I went back to my room and I was tired. And it was a long walk, and I’d have to rest against the wall partway, and then carry on after a bit. So I said there is something wrong with me. Like I couldn’t go all night without getting up to use the washroom. And like when you get up 2 or 3 times in the night, that’s too much when you are 36. (Participant 12)
As finding a path	It’s not fun. Pain is not fun, and suffering is not fun. But in the end, move forward and help and just do the best you can. So never lose faith. It’s all about faith and it’s all about hope. (Participant 01) I was sad [at receiving the diagnosis of MS]. The way I can put it is when you’re a kid growing up, you have an idea of what your life is going to be. And most people… I mean obviously there are twists and turns, and they don’t end up being that. But everything I thought I was, it was like done. So I have to re-write the script. (Participant 03) That’s one of my goals with this thing, is to help people see that it doesn’t have to be this monstrous mushroom cloud. And if I can help people, you know, just to realize there are going to be really tough times, dark times, and we need to understand the really difficult times. But we also have to balance that with how we can encourage the strengths and resources that you have. (Participant 06) Well, sometimes you sort of have to forget those memories, what you did and what happened in the past, you want to try to concentrate on the present and the future. Not dwell on the past. It’s a person’s choice whether they want to live for the day or yesterday or tomorrow. (Participant 11)

5.5. Discussion

The purpose of this study was to explore how persons with MS describe their experiences of specific components of resilience: *adapting to MS, coping with MS, social support and wellness.* The participants' responses reflected a mix of both positive and negative experiences related to each of these components. In the MS literature, these components are often referenced in positive terms only, as resilience resources. The reality is that for many, these "resources" also have aspects of difficulties or challenges. Findings from this study suggest that it is important not to approach adapting, coping, support and wellness in a unidimensional, simplistic manner, rather to acknowledge the difficulties in addition to the positive aspects of living.

Psychological adaptation to disability has been defined as how individuals with disabilities perceive, assess, cope with, and gradually assimilate various changes in body, self, and personal-environment interactions necessitated by their impairments[42]. In this study, the participants' responses reflected this definition of adaptation insofar as they talked about setting realistic self-expectations, incorporating assistive devices and medications into daily life, delegating tasks to others, and dealing with the complexities of family and social roles and responsibilities. Thus, for participants in this study, adaptation was understood to involve making external modifications because of the MS, with a focus on modifying their home, work, and social environments. It is generally accepted that adapting to impairments associated with chronic diseases suggests adaptation is rarely required only once, but rather required repeatedly by persons as they experience new functional losses[43]. This is especially true of adapting to MS, which in the current study was seen by participants as requiring change and adjustment to accommodate a decreased level of function in body and or mind, maintaining that level until function declined again, and then changing and adjusting again.

The above definition of psychological adaptation posits that coping is a facet of adaptation[42]. The generally accepted definition of coping is the deliberate cognitive and behavioural efforts persons undertake to manage a stressful situation or event[44]. In the current study, the participants talked about coping primarily in terms of cognitive and emotional efforts and internal changes; whereas adaptation was talked about primarily in terms of behavioral and external changes. If the distinctions made by this study's participants between the concepts of adaptation and coping are more widespread, it may have implications for how persons with MS, MS clinicians and researchers develop a common understanding of adaptation and coping.

There is no generally agreed strategy for classifying ways of coping. However, the typology articulated by Lazarus and Folkman, emotion-focused coping and problem-focused coping, is widely cited[44,45]. Emotion-focused coping involves strategies directed at regulating the emotions that come with the stressful situation, while problem-focused coping involves strategies directed at altering or managing the situation causing the stress[46]. Both types are used by persons with MS with a tendency for emotion-focused coping strategies to be used more during times of high levels of distress and problem-focused coping strategies used more during times of low levels of distress[46,47]. The participants interviewed in this study embraced both methods of coping. Interestingly, denial, widely considered a negative type of emotion- focused coping, was seen by this study's participants as very effective in the early stages of MS in dealing with the emotional repercussions of the diagnosis, perhaps as a way to slowly accommodate to the fact they had a chronic disease with no cure. Then later, as the diagnosis became less overwhelming and other practical problems associated with the disease became more problematic, more positive emotion-focused coping (such as faith, acceptance and positive thinking) and problem-focused strategies (e.g., knowledge seeking) were used.

As above, faith was a common way of coping used by these participants. This included faith in God, in themselves, and in medical advances. “Faith” is referenced in the literature as including religious beliefs[48] but also as including faith in oneself and faith in one’s partners and family to provide support[49]. Faith in medical advances appears to have fluctuated in the recent past, as evidenced by research conducted to examine why some persons with MS decided to pursue such unproven, risk laden interventions as “liberation therapy” (treatment for chronic cerebrospinal venous insufficiency (CCSVI) – an angioplasty procedure for opening blocked or narrow veins to allow better blood flow and drainage from the brain)[50]. Presently, there is some evidence that persons with MS appear to be taking a more balanced approach with regard to MS treatments, combining research-based non-pharmaceutical interventions such as diet and exercise with medications[51]. There is a cautious optimism amongst persons with MS that current research trials will result in effective therapies[52]. This cautious optimism was expressed by this study’s participants as well, in that they knew research took a long time and not every trial would end with positive results, but research had led to the current treatments for modifying the disease, and they expressed gratitude for these advances as well as the continuing investment in MS research.

Similar to how coping is a major theme in the MS psychological adaptation literature, social support is often considered an important aspect of coping. Coping strategies, such as seeking social connections, information and exchange of experience, were more likely to occur for persons who receive support from family, friends and others with MS, than those persons without support[53]. In addition to being an important factor in helping persons with MS cope[54], greater social support is associated with mental health facets such as less depression and anxiety, higher quality of life[55-57]. While family is a primary source of support, social networks beyond family, including friends with and without MS, and support groups, both MS-specific and common interest groups, appear to be integral to how well persons with MS adapt to and cope with MS[53,58,59]. The descriptions of social support provided by the participants align with this research, with family cited as a primary source of support and community groups being a very important part of their social support framework. Family support was complex, however. The participants valued the ability to lean on their family but also disclosed times of strained connections and sustaining distance. This is borne out in other studies as well, in particular those studies addressing caregiver burden[60,61]. Caregivers of persons with MS are also dealing with the disease of MS and also face an unpredictable future[60,62]. Family cohesion and quality communication help both the person with MS and the caregiver to support each other, whereas support is strained when there is disengagement and poor or lack of communication[61]. There is often a mix of both positive and negative experiences in being a family caregiver[63]. Thus, interventions to help caregivers strengthen the positive aspects, such as re-framing time spent together as quality time, and services to lessen the burdens, such as access to house cleaning services and financial assistance with obtaining equipment, could be essential ways to maintain and improve the relationships between the persons with MS and the caregiver[49,60-63].

Another aspect of social support discussed by participants, seeking expertise, speaks to the importance role health care providers and organizations such as the MS Society play in the lives of persons with MS. In this study, participants highlighted the need to share openly and honestly with someone external to friends and family about what they were experiencing, as they sometimes felt they shouldn't burden family by being completely forthright. They also spoke to the need for knowledge exchange, guidance and connection to other resources. Having social support from a multitude of sources, family, friends, others with MS, support groups, and health care professionals and societies can give persons with MS the tangible and emotional support they require for coping with and adapting to MS[53]. Persons without support tend to have a much more difficult time coping and adapting and, as a result, tend to have poorer health and well-being outcomes[64,65].

Improving the physical health and psychosocial well-being of persons with MS is the goal of a wellness initiative recently embarked upon by the National MS Society (NMSS) of the United States[51]. The working group cites the definition of wellness as "an active process through which people become aware of, and make choices toward, a more successful existence (www.nationalwellness.org)" and asserts that wellness is important for optimizing the physical, mental and social health-related quality of life of persons with MS. The participants in this study described wellness as managing symptoms and finding a path. Underscoring the participants' descriptions was a desire to strive for wellness. Even though the participants generally said they did not feel well physically, they viewed wellness as possible despite their physical state.

The findings regarding wellness in this study suggest persons with MS view wellness as more than just their physical health. However, it is also clear from the participants' responses that assessment and management of symptoms is critical to their well-being. The symptoms of MS often cluster (e.g., depression, fatigue and sleep disturbances) requiring the assistance of health care specialists to manage the interconnections of these symptoms well[66]. Symptom management is a key factor in MS care and needs to continue to be a focus of MS research and interventions[57,66]. By addressing symptoms, including psychological symptoms such as depression, emotional wellness is also addressed.

There is growing evidence that, in general, work is beneficial for health and well-being[67,68]. Even part-time work has a positive effect on mental health[69]. Yet participants in the current study often found themselves unable to sustain part-time employment, because workplace settings were not flexible enough to accommodate their needs. Employment of those with MS related disabilities has been shown to be possible where employers have an awareness and understanding of the disease, clear productivity expectations, the ability to be flexible with work hours and responsibilities, and there are benefits such as sick days and disability benefits[70]. That it is possible for those with MS to sustain employment despite disabilities is shown by the success of programs and services aimed at helping persons with MS know when and how to disclose their diagnosis to their employers; proactive consideration of options for re-training or pursuit of work accommodations; how to navigate government and insurance company plans; and how to successfully adapt to changing abilities in regards to employment[70,71].

It is clear from this study that adaptation, coping, social support and wellness have both positive and negative aspects. This is consistent with the findings in the other known qualitative study on resilience in MS which described participants' perspectives on facilitators of and barriers to resilience[29]. There is certainly the potential for adapting, coping, social support and wellness to serve as important resilience resources. This was supported by participants' common intent and desire to develop and strengthen positive aspects and to acknowledge and work through negative aspects. There was recognition of ways and opportunities to adapt and cope better, seek and grow a healthy and understanding support network, and pursue mental and emotional wellness despite uncertain and/or declining physical health and abilities. Acknowledging and working through the negative aspects of adapting, coping, support and wellness may shift these aspects from “potential” resources to “actual” resources.

A few limitations of this study need to be noted, as they may impact the transferability of the findings[33,72]. The sample was a convenience sample of participants who agreed to be contacted about future studies on resilience after taking part in the larger quantitative study regarding resilience and MS. The persons who volunteered for this study were more disabled than the larger study from which the sample was drawn, and their health-related quality of life score was lower than the larger sample. In addition, there was a higher percentage of persons not working due to their MS and who had progressive forms of the disease. Their fatigue scores and resilience scores were slightly poorer, although without knowing the threshold for minimal clinically important differences on these measures, it is unclear how to judge the importance of these differences in scores. Their scores on the anxiety, depression, stress and social support measures were virtually the same. One participant lived in a long-term care centre, whereas the other eleven lived in their own homes. Still, the participants in this qualitative study had a range of disability levels and a range of disease durations, and thus the descriptions of adapting, coping, social support, and wellness came from various perspectives of time living with the disease and degree of impairment experienced.

The number of resilience components explored was limited to four to minimize respondent burden. Other resilience components, such as setting and pursuing goals, having a purpose in life, and health-related quality of life, were raised by the participants as part of adapting, coping, support and or wellness but were not specifically focused on during the interview. Though the breadth of potential resilience resources and vulnerabilities were not captured in this study, the study findings provide depth of insight into how these four aspects can be experienced as both resources and as vulnerabilities.

5.6. Conclusions

The findings from this qualitative study expand the body of knowledge on how those with MS adapt to and cope with MS and clearly point out both the beneficial and not so beneficial roles played by family, friends and employers of those with MS. Further, the study's findings provide a glimpse into how those with MS experience wellness. This information can be used to inform further research questions such as how to strengthen resilience among persons with MS and what impact those efforts will have. Findings from the current study suggest that resilience intervention studies would need to address both internal and external resources such as navigating roles and responsibilities, knowledge seeking, leaning on others, and managing symptoms. At the same time, acknowledgement needs to be given to some of the challenges likely to be encountered such as the continuous need to adjust to changing abilities and the way the connections with family and friends can be strained. To date, the research on resilience in MS suggests resilience may be an important component in physical, mental and social health and well-being outcomes. To optimize resilience, we must know and understand how resources and vulnerabilities are experienced in order to build resources and mitigate vulnerabilities.

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CHAPTER 6: Discussion and Significance of Study Findings

6.1. Overview of the Study Findings and Connections between the Quantitative and Qualitative Findings

Three studies comprise the body of this thesis work that focused on resilience and resilience resources and vulnerabilities. The first was a survey of persons living with MS. Nine factors were associated with greater resilience: (1) *older age*; two types of coping, (2) *acceptance* (an ability to manage, get used to, cope with and accept the illness) and (3) *cognitive/palliative coping* (faith, beliefs, being able to think of worse situations and learning as much as possible about the illness); two constructs of hope, (4) *goal setting* and (5) *goal planning*; and four constructs of psychological well-being, (6) *autonomy* (self-determining and independent), (7) *environmental mastery* (managing the environment, making use of opportunities, choosing or creating contexts suitable to personal needs and values), (8) *personal growth* (continued development) and (9) *self-acceptance* (positive attitude, accepting good and bad qualities of oneself).

The second study utilized data from the first study and uncovered salient features of resilience in persons with MS through factor analysis of the Connor-Davidson Resilience Scale 25-item instrument (CD-RISC-25)[1]. These factors were: (1) *positive acceptance of change* (able to adapt, deal with, use humour, cope with stress, bounce back, stay focused), (2) *personal competence* (solve problems on own, make difficult decisions, work to attain goals, take pride), (3) *secure in oneself and others* (have close relationships, know where to turn for help, able to handle unpleasant or painful feelings, have a sense of purpose of life, feel in control), (4) *perseverance* (give best effort, believe one can achieve goals, not give up, not be easily discouraged) *and* (5) *spiritual influences* (believe fate or God can help, believe things happen for a reason). These findings were largely supportive of the findings in the first study. The factor of positive acceptance of change aligns with acceptance (as a coping strategy) and self-acceptance (an aspect of psychological well-being) from the first study. Similarly, the factor of personal competence in the second study aligns with cognitive-palliative coping, goal setting and goal planning (hope), and autonomy and environmental mastery (psychological well-being) from the first study. The factor of feeling secure in oneself and others in the second study mirrors aspects of autonomy and environmental mastery in the first. Perseverance aligns with goal setting, goal planning and personal growth. Lastly, the fifth factor in the second study, spiritual influences, is seen in the factor of cognitive/palliative coping. It is perhaps not surprising that there is close alignment between the group of psychosocial constructs (coping, hope and psychological well-being) found to be related to resilience and the factor structure of the resilience measure used, since both studies used the same database of self-reported information. Further research is needed to confirm both the factor structure of the CD-RISC-25 in those with MS and factors associated with resilience in MS.

The third study described how persons with MS experience four specific components of resilience: *adapting, coping, social support and wellness*. Adapting to MS was described by the participants as changing self-expectations, living differently, navigating roles and responsibilities and adjusting to continually changing abilities. Coping with MS was described as acceptance, perspective, knowledge seeking, denial and faith. Social support was experienced as leaning on others, strained connections, community, sustaining distance and seeking expertise. Wellness was described as managing symptoms and finding a path. These findings provide depth of knowledge to the quantitative findings in studies 1 and 2. For example, the concept of environmental mastery (study 1) and personal competence (study 2) was seen in how the participants articulated living differently as part of adapting to MS – figuring out how to incorporate therapies, medication and aids into daily life. Elements of personal growth (study 1) and perseverance (study 2) were seen in the participants' descriptions of how they had to adjust to continually changing abilities as part of adapting. The nuances of acceptance, as constructs of coping and psychological well-being (study 1) and positive acceptance of change (study 2), were illustrated as accepting one's self and situation, finding life activities within one's control, doing the best they could, letting go of past goals and plans and setting and pursuing new ones, and framing their struggles affirmatively as part of coping with MS. Faith as a component of cognitive/palliative coping (study 1) and spiritual influences (study 2) was also talked about by the qualitative participants but in more ways than religious faith. The participants also talked about faith in oneself and in medical advances, suggesting that perhaps the definition of faith and or spirituality needs to be expanded when explored in relation to resilience among persons with MS. The complexities surrounding social support were illuminated, including the possibility of strain in relationships, negative focus in support groups, and perceived risk of losing support if too much information is shared. The fact that, for those with MS, social support would appear to have both positive and negative aspects may provide some insight into why social support was not associated with resilience in the first study.

The health-related quality of life (HRQL) scores for survey participants were low and were even lower for participants in the smaller, qualitative study. The descriptions of how wellness is experienced reflected this. Wellness was described in terms of having to manage physical and mental/psychological symptoms, but there was also a desire to find a path towards wellness despite these symptoms. The HRQL questionnaire used in the survey (HUI3) asks about eight health attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain[2]. These measured attributes align with the most troublesome symptoms experienced by participants in study 3, that is visual disturbances, ambulation difficulties, depression, cognitive difficulties and pain. This information from the qualitative study supports the idea that this HRQL measure is useful for those with MS.

Despite the low HRQL scores from the cross-sectional survey as a whole and from the subsample used for the qualitative study, the resilience scores were higher than those reported in studies of patients with chronic back pain and in patients with psychiatric conditions[3, 4]. The qualitative participants described wellness as finding a path that was further delineated as finding a “new normal”, being realistic about the future, and appreciating “glimmers” and “moments” of wellness found in a hug, a joke, or a piece of music. The participants expressed a desire to define and pursue new goals, a willingness to accept and face future challenges, and an acknowledgement that they had more to be hopeful about regarding MS care and treatment than in the past. These findings align well with the factors that were found to be associated with resilience in study 1, particularly goal setting and planning, acceptance and personal growth, as well as with the factor analysis in study 2, especially positive acceptance of change, personal competence and perseverance.

6.2. Significance of the Study Findings

To the best of this author's knowledge, this is the first study to report resilience scores using the CD-RISC-25 and its shorter version, the CD-RISC-10, in a Canadian MS sample, as well as the first study to explore the factor structure of the measures in those with MS. Both versions of the CD-RISC demonstrated excellent internal consistency. Further MS-specific research is required regarding the validity of the five-factor model that emerged from the exploratory and confirmatory factor analyses of the CD-RISC-25, as only construct validity was explored in this study, and there are other important ways to assess validity such as discriminant validity. Thus, while the five factors emerging from the factor analysis should not be used as sub-scale measurements of resilience, they provided insight into what the underlying constructs may be for resilience in those with MS.

While adaptation and coping have been identified as resilience resources in other qualitative studies of persons with MS[5-7] and hope and psychological well-being have been found to be associated with resilience in studies of those with various types of physical disabilities[8], the research in this thesis helps to bring these findings together. The fact that goal setting explained a high percentage of the variance in resilience is an important finding, as there has been little focus to date on this in MS studies. One step in this direction was the pilot study that included goal setting as part of a positive psychology intervention program in which those receiving the intervention showed improvements in resilience[9]. However, as goal setting was only one component of the program, it is unknown what percentage of the improvement can be attributed to goal setting alone. Another pilot intervention study, investigating the feasibility of Acceptance and Commitment Therapy (ACT), included training on aspects arguably similar to goal setting (meaningful action, discovering and committing to actions that focus on things that care about). This pilot study also showed improvements in resilience after treatment[10]. However, as there was no comparison group, firm conclusions cannot be made about the effectiveness of this resilience intervention. These studies provide promising glimpses of the importance of goal setting in building resilience in those with MS. However, this body of research is very preliminary and additional research is needed to understand the role of goal setting in resilience in persons with MS.

Acceptance was a recurring finding in all three of the thesis studies: acceptance as a facet of coping, self-acceptance as a facet of psychological well-being, and positive acceptance of change. There is also some preliminary evidence that acceptance is amenable to intervention, since it also showed improvement in the ACT pilot study mentioned above[10]. Again, lack of a comparison group makes it difficult to make any firm conclusions.

There have been few qualitative studies on resilience in those with MS, and this is the first to explore how those with MS describe their experiences with aspects of resilience resources and vulnerabilities in their daily lives. A critical finding was that there were both positive and negative aspects to what we might otherwise consider uncomplicated resources. This understanding has implications for designing resilience-based interventions and serves as a caution to acknowledge and work through some of the negative aspects of what we might otherwise consider resources. This includes the understanding that, along with social support systems of family and friends, also may come family tensions and reluctance to burden members of this network.

MS is a disease of uncertainty, variability and progression[11]. These characteristics place physical, mental and social strain on persons living with the disease[12]. However, in spite of this adversity, persons with MS may be able to recover emotionally from setbacks, sustain a sense of purpose and meaning within the context of a chronically changing life, and gain new insights and enhance their capacity for overcoming difficult and ongoing stressors[13]. The premise that persons can learn and develop resilience knowledge and skills is a key part of the framework to understanding resilience in chronic diseases such as MS[14]. As adapting, coping, hope and psychological well-being are potentially modifiable, knowledge and skill development in these areas could strengthen the resilience of persons with MS. Goal re-engagement (extent to which one considers oneself able to reengage in alternative meaningful goals in the case that pre-existing goals are no longer reachable) is a potentially promising direction in helping those with MS[15]. Building a supportive social network involves building on the positive aspects of relationships with family and friends and managing any negative aspects, and includes MS health care providers and MS support organizations as potential sources of support[16,17]. Symptom management interventions should of course continue to be a focus of MS research to lessen the impact of symptoms as much is possible[18].

This thesis work adds to our understanding of factors associated with resilience in MS, and how persons with MS experience resilience, and represents an initial step towards the ultimate goal of strengthening resilience resources and decreasing and managing resilience vulnerabilities. Greater resilience may, in turn, result in better health and well-being outcomes for persons with MS.

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CHAPTER 7: Future Directions and Conclusion

7.1. Future Directions

The majority of studies on resilience in MS are cross-sectional in nature. Longitudinal studies are needed to uncover the strength and direction of the relationships between potential resources and vulnerabilities with resilience. As with other research findings, replication of the studies comprising this thesis using other samples of persons living with MS is required to confirm the findings, as all three studies provide new insights into our understanding of resilience among persons with MS. Investigation into the role resilience has in health and well-being outcomes is also warranted (e.g., its possible role as a mediator or moderator in the association between other factors and health outcomes).

As we gain a better understanding of the role of resilience in the health and well-being of those with MS and a better understanding of the key components of resilience, interventions designed to improve resilience can be developed and tested. Along with that is the need to understand when, in the course of MS, interventions are likely to be most effective and who is likely to benefit most from such interventions.

Qualitative research provides depth of knowledge to the breadth that is established via quantitative research. Additional qualitative research is needed to understand how persons with MS describe their experiences with other components of resilience such as setting and pursing revised goals, having a purpose in life and dealing with uncertainty. This knowledge will be useful in clinical settings and in developing effective interventions.

Regarding the measures used in the studies, research is required to understand the minimal clinically important difference (MCID) in the CD-RISC-25 and CD-RISC-10 in the MS population in order to judge the success of interventions designed to increase resilience. The social support scale used in the survey focuses on support from significant others, families and friends. The findings from these studies and the literature suggest supports from MS health care professionals and organizations are also important to those with MS and should be included in MS-specific social support measures. Further, it may be the quality or satisfaction with social support that is the important aspect of social support rather than quantity. Measures assessing faith and spirituality influences as they relate to resilience may also need to be expanded beyond religious beliefs to include faith in oneself and others and in MS research.

7.2. Conclusions

Resilience, the adaptive response to adversity, provides a framework that explicitly accounts for personal and environmental resources in addition to risks and vulnerabilities. The findings from this thesis work lay groundwork for future research aimed at promoting the health and well-being of those living with MS through recovery, sustainability, and growth-strengthening resilience initiatives.

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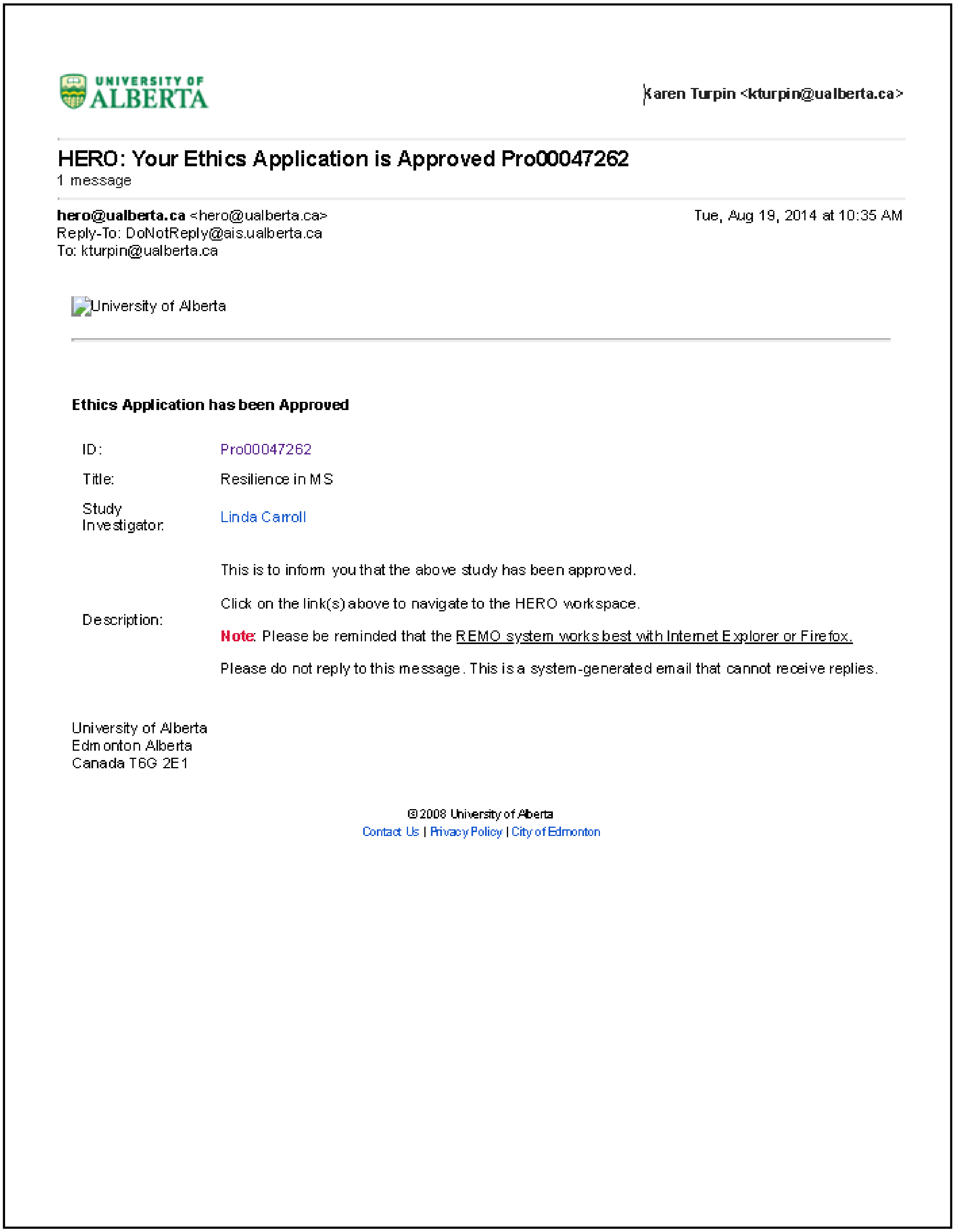
APPENDIX A – University of Alberta Ethics Certificate



Karen Turpin <kturpin@ualberta.ca>

HERO: Your Ethics Application is Approved Pro00047262

1 message

hero@ualberta.ca <hero@ualberta.ca> Tue, Aug 19, 2014 at 10:35 AM
Reply-To: DoNotReply@ais.ualberta.ca
To: kturpin@ualberta.ca

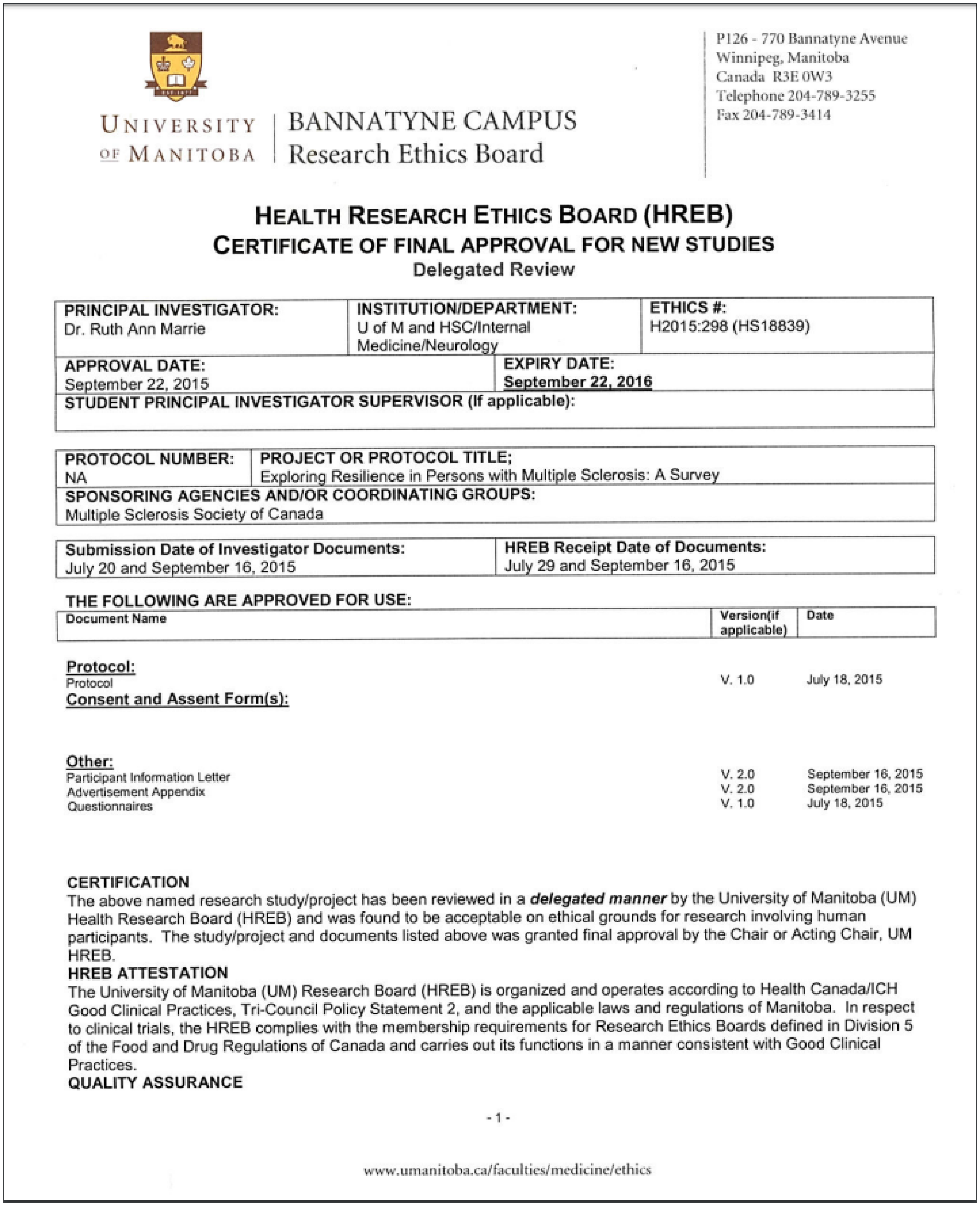
University of Alberta

Ethics Application has been Approved

ID:	Pro00047262
Title:	Resilience in MS
Study Investigator:	Linda Carroll
Description:	This is to inform you that the above study has been approved. Click on the link(s) above to navigate to the HERO workspace. **Note**: Please be reminded that the REMO system works best with Internet Explorer or Firefox. Please do not reply to this message. This is a system-generated email that cannot receive replies.

University of Alberta
Edmonton Alberta
Canada T6G 2E1

APPENDIX B – University of Manitoba Ethics Certificate



UNIVERSITY OF MANITOBA | BANNATYNE CAMPUS
Research Ethics Board

P126 - 770 Bannatyne Avenue
Winnipeg, Manitoba
Canada R3E 0W3
Telephone 204-789-3255
Fax 204-789-3414

HEALTH RESEARCH ETHICS BOARD (HREB)
CERTIFICATE OF FINAL APPROVAL FOR NEW STUDIES
Delegated Review

PRINCIPAL INVESTIGATOR: Dr. Ruth Ann Marrie	**INSTITUTION/DEPARTMENT:** U of M and HSC/Internal Medicine/Neurology	**ETHICS #:** H2015:298 (HS18839)
APPROVAL DATE: September 22, 2015	**EXPIRY DATE:** September 22, 2016	
STUDENT PRINCIPAL INVESTIGATOR SUPERVISOR (If applicable):		

PROTOCOL NUMBER: NA	**PROJECT OR PROTOCOL TITLE;** Exploring Resilience in Persons with Multiple Sclerosis: A Survey
SPONSORING AGENCIES AND/OR COORDINATING GROUPS: Multiple Sclerosis Society of Canada	

Submission Date of Investigator Documents: July 20 and September 16, 2015	**HREB Receipt Date of Documents:** July 29 and September 16, 2015

THE FOLLOWING ARE APPROVED FOR USE:

Document Name	Version(if applicable)	Date
Protocol:		
Protocol	V. 1.0	July 18, 2015
Consent and Assent Form(s):		
Other:		
Participant Information Letter	V. 2.0	September 16, 2015
Advertisement Appendix	V. 2.0	September 16, 2015
Questionnaires	V. 1.0	July 18, 2015

CERTIFICATION
The above named research study/project has been reviewed in a ***delegated manner*** by the University of Manitoba (UM) Health Research Board (HREB) and was found to be acceptable on ethical grounds for research involving human participants. The study/project and documents listed above was granted final approval by the Chair or Acting Chair, UM HREB.

HREB ATTESTATION
The University of Manitoba (UM) Research Board (HREB) is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement 2, and the applicable laws and regulations of Manitoba. In respect to clinical trials, the HREB complies with the membership requirements for Research Ethics Boards defined in Division 5 of the Food and Drug Regulations of Canada and carries out its functions in a manner consistent with Good Clinical Practices.

QUALITY ASSURANCE

- 1 -

www.umanitoba.ca/faculties/medicine/ethics

APPENDIX C – Information Letter for Cross-sectional Survey

PARTICIPANT INFORMATION LETTER

Title of Study:	Exploring Resilience in Persons Living with MS: A Survey
Principal Investigator:	Dr. Linda Carroll, Professor School of Public Health, University of Alberta Phone: 780.492.9767 E-mail: lcarroll@ualberta.ca
Co-Investigators:	Ms. Karen Turpin, MSc, BScN PhD Candidate, School of Public Health, University of Alberta Phone: 780.492.9230 E-mail: kturpin@ualberta.ca **(*And study coordinator for this study)**
	Dr. Ruth Ann Marrie Director, Winnipeg MS Clinic, University of Manitoba
	Dr. Penny Smyth MS Specialist, Edmonton MS Clinic, University of Alberta

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Why am I being asked to take part in this research study?

For the more than 100,000 Canadians with multiple sclerosis (MS), there is a lot of uncertainty about how their disease may affect them. This uncertainty can cause immense emotional strain on those living with MS and their families. We need to find ways to enable those with MS to maximize their well-being and quality of life.

Resilience is emerging as key in promoting health and well-being of those living with a chronic illness. However, we know little about resilience among persons with MS. The research team listed above would like to do a study on resilience in MS.

Before you make a decision regarding your participation in this study, please read over the following information. Please also ask us if you have any questions – contact Karen Turpin at kturpin@ualberta.ca or 780-492-9230. Please keep a copy of this form for your records.

What is the reason for doing this study?

The purpose of this study is to measure resilience among people living with MS and to explore factors that might strengthen resilience, and factors that might weaken it.

The hope of the research team is that the results from this study will be the beginning of a research program aimed at promoting the health and well-being of those living with MS through strengthening resilience (*Strengthening H.O.P.E. in Multiple Sclerosis through Resilience – Healthier Outcomes and Positive Experiences)*.

What will I be asked to do?

If you agree to be in this study, we would ask you to:

- Choose a time of day to do the survey when you feel you are most alert. If mornings are better, schedule some time do it then, or perhaps in an evening, or on the weekend.
- We estimate the survey will take about 45 minutes to complete.
- Feel free to take breaks.
- You can minimize the survey and come back to it, or you save & continue later (instructions provided within the survey).
    - It will stay open until you decide to submit the survey, if you have minimized it. If you choose to save it to come back to it later, it will remain active until you submit it.
    - None of your answers will be recorded until the submit button is clicked. If you accidentally close the survey before submitting, your answers will be lost and you will need to start over. If you chose the save and continue later option, you can pick up from where you left off. You still need to click the submit button for your answers to be recorded in the database.
- Contact Karen Turpin, at anytime, if you have any questions or concerns at 780-492-9230 or kturpin@ualberta.ca
- If willing, at the end of the survey provide your name and contact information, so that in the event of follow-up studies on resilience, the research team can contact you to see if you might be interested in participating. By giving us your information, it does not mean you are agreeing to a part of future studies, just that you are willing to learn more about them and decide at that time if you'd like to participate or not.

What are the potential risks and discomforts?

The study has minimal risks. It is possible that some of the survey' questions may make you feel uncomfortable because they will make you think about your MS and its impact on your life. You can refuse to answer any questions that you do not want to answer. If at any time you feel uncomfortable, or have any questions or concerns, please feel free to contact Karen Turpin.

It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?

Your participation in this study will help the research team have a better of understanding of resilience and what may strengthen it and what may weaken it among those living with MS. The results of the study may help MS health care providers and researchers know how resilience might be strengthened. You may not get any benefit from being in this research study.

Do I have to take part in this study?

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the care that you receive.

Your participation in this research is voluntary. Your decision to participate will not affect your current or future relations with your MS doctor or the MS Clinic, or any organization through which you heard about this study, such as the MS Society. You may refuse to answer any questions you do not want to answer and remain in the study.

If you decide to take part in this study, your consent to be a participant is implied when you complete and submit the survey.

Will my information be kept private?

During the study, we will be collecting information about you. We will do everything we can to make sure that this data is kept private. No information relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

If you agree to provide to provide your name and contact information at the end of this study, this information will be stored separate from the survey data.

We will keep your responses confidential. Only the research team (Dr. Carroll, Marrie, Smyth and Ms. Turpin) will have access to this information. When we share the results of this study, no information will be included that would reveal your identity. Any information that you provide through the study will remain confidential.

All the study information collected from you will be stored in a safe and locked location in the University of Alberta. We will keep your data for at least 5 years after it is analyzed and published. Your name will not appear on any documents related to your participation in this study.

What if I have questions or concerns?

If you have any questions about this research study now or later, please contact Ms. Karen Turpin at 780-492-9230 or kturpin@ualberta.ca

If you have any questions or concerns regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

Thank you for your consideration!

APPENDIX D – Information Letter and Consent Form for Qualitative Interviews

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PARTICIPANT INFORMATION LETTER

Title of Study: Exploring Resilience in Persons Living with MS: A Qualitative Study

Principal Investigator: Dr. Linda Carroll, Professor
School of Public Health, University of Alberta
Phone: 780.492.9767
E-mail: lcarroll@ualberta.ca

Co-Investigators: Ms. Karen Turpin, MSc, BScN
PhD Candidate, School of Public Health, University of Alberta
Phone: 780.492.9230
E-mail: kturpin@ualberta.ca
(*And study coordinator for this study)

Dr. Ruth Ann Marrie
Director, Winnipeg MS Clinic, University of Manitoba

Dr. Penny Smyth
MS Specialist, Edmonton MS Clinic, University of Alberta

Dr. Michael van Manen
Neonatologist, University of Alberta

Why am I being asked to take part in this research study?

For the more than 100,000 Canadians with multiple sclerosis (MS), there is a lot of uncertainty about how their disease may affect them. This uncertainty can cause immense emotional strain on those living with MS and their families. We need to find ways to enable those with MS to maximize their well-being and quality of life.

Resilience is emerging as key in promoting health and well-being of those living with a chronic illness. However, we know little about resilience among persons with MS. The research team listed above would like to do a study on resilience in MS.

Before you make a decision regarding your participation in this study, please read over the following information. The study coordinator, Karen Turpin, will go over the letter with you. Please feel free to ask her any questions you may have about this study. Please keep a copy of this form for your records.

What is the reason for doing this study?

The purpose of this study is to understand resilience among people living with MS and to explore factors that might strengthen resilience, and factors that might weaken it.

The hope of the research team is that the results from this study will be the beginning of a research program aimed at promoting the health and well-being of those living with MS through strengthening resilience (*Strengthening H.O.P.E. in Multiple Sclerosis through Resilience – Healthier Outcomes and Positive Experiences)*.

What will I be asked to do?

If you agree to be in this study, we would ask you to:

- Take part in a 1 hour interview with the study coordinator, Karen Turpin.
- The interview will take place at the University of Alberta, or at an agreed upon private and quiet location.
- You will be asked to think and tell about some experiences you may have had adapting to stress and adversity, and the highs and lows of having MS.
- The interview will be tape-recorded so it can be transcribed (typed out) so Karen can look for common patterns and themes amongst the interviews.
- You may be asked to review a draft of the write up of the interviews to get your feedback. This would be done over the phone.
- You will be given $50 to reimburse you for your expenses.

What are the potential risks and discomforts?

The study has minimal risks. However, it is possible that some of the experiences you may be telling the interviewer, Karen Turpin, may make you feel uncomfortable because they will make you think about your MS and its impact on your life. You can stop the interview at any time, or take a break. You can refuse to answer any questions that you do not want to answer.

It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?

Your participation in this study will help the research team have a better understanding of resilience and what may strengthen it and what may weaken it among those living with MS. The results of the study may help MS health care providers and researchers know how resilience might be strengthened. You may not get any benefit from being in this research study.

Do I have to take part in this study?

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the care that you receive.

Your participation in this research is voluntary. Your decision to participate will not affect your current or future relations with your MS doctor or the MS Clinic, or any organization through which you heard about this study, such as the MS Society. You may refuse to answer any questions you do not want to answer and remain in the study.

Will my information be kept private?

During the study, we will be collecting information about you. We will do everything we can to make sure that this data is kept private. No information relating to this study that includes your name will be released outside of the researcher's office or published by the researchers.

If you agree to provide your name and contact information at the end of this study, this information will be stored separate from the interview data.

We will keep your responses confidential. Only the research team (Dr. Carroll, Marrie, Smyth, van Manen and Ms. Turpin) will have access to this information. When we share the results of this study, no information will be included that would reveal your identity. We will give you a false name (pseudonym) if we decide to use names in reporting our findings. For example, Jane said…, John was… Sally read… Any information that you provide through the study will remain confidential.

All the study information collected from you will be stored in a safe and locked location in the University of Alberta. We will keep your data for at least 5 years after it is analyzed and published. Your name will not appear on any documents related to your participation in this study.

What if I have questions or concerns?

If you have any questions about this research study now or later, please contact Ms. Karen Turpin at 780-492-9230 or kturpin@ualberta.ca

If you have any questions or concerns regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

Thank you for your consideration!

PARTICIPANT CONSENT FORM

Title of Study: Exploring Resilience in Persons Living with MS: A Qualitative Study

Principal Investigator: Dr. Linda Carroll, Professor
School of Public Health, University of Alberta
Phone: 780.492.9767
E-mail: lcarroll@ualberta.ca

Co-Investigators: Ms. Karen Turpin, PhD Candidate
School of Public Health, University of Alberta
Phone: 780.492.9230
E-mail: kturpin@ualberta.ca
(*And study coordinator for this study)

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your future medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records?	☐	☐
Do you want the investigator(s) to inform your family doctor that you are participating in this research study? If so, give his/her name:	☐	☐

____

Who explained this study to you?

____

I agree to take part in this study:

Signature of Research Participant ____

(Printed Name) ____

Date:____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

This should be signed by the person who is conducting the informed consent discussion (if that is not the Investigator – the person that obtained the consent needs to sign here)

Signature of Investigator or Designee____________________________ Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

APPENDIX E – Resilience in Multiple Sclerosis Questionnaire

UNIVERSITY OF ALBERTA

Welcome to the Resilience in Multiple Sclerosis Questionnaire!

- For the more than 100,000 Canadians with multiple sclerosis (MS), there is a lot of uncertainty about how their disease may affect them.
- We need to find ways to help those with MS improve their overall sense of health and well-being.
- The concept of resilience is emerging as an important aspect in the promotion of the health and well-being of those living with a chronic illness.
- To date, very little research has been done on resilience among persons with MS. We would like to do a study on resilience in MS.

This questionnaire contains 6 sections:

1. Section A – Living Life
2. Section B – Managing Life
3. Section C – Experiencing Life
4. Section D – Impact of Your MS
5. Section E – About You
6. Section F – About Your MS

Before you begin, we would like to answer the following questions to be sure you are eligible to do the survey:

1. I am at least 18 years old ☐ Yes ☐ No
2. I have had MS for at least 2 years ☐ Yes ☐ No
3. I have a confirmed diagnosed of MS from a doctor ☐ Yes ☐ No

If you answered no to any of the above questions, we thank you for your time and interest in our study, but you will be unable to take part. If you have any questions or concerns about your eligibility to participate in this study, you may contact Karen Turpin, study coordinator, at 780-492-9230 or kturpin@ualberta.ca

Some important notes before you begin:

1. **Do the survey whenever it works best for you.** If you feel more alert and energetic first thing in the morning, do the survey then, if your best time is in the evening, consider doing it then. If there is a day of the week that is better, maybe schedule some time in to begin the survey that day.

2. **Take breaks!** You do NOT have to do the entire survey in one sitting. Please feel free to do one section at a time, take a break, and come back to it. You can even do the survey over a few days if you'd like. We'd like it though if you could complete the entire survey in one week's time.

3. **Read the following information letter.** It contains more detailed information about the study, how confidentiality will be maintained, and provides contact information for the study team.

4. **Contact Karen Turpin**, study coordinator, at 780-492-9230 or kturpin@ualberta.ca if you have any questions or concerns.

Thank you!

Section A: Living Life

A-1 For each item, please mark with an “x” in the box below that best indicates how much you agree with the following statements as they apply to you **over the last month**. If a particular situation has not occurred recently, answer according to how you think you would have felt.

	Not true at all	**Rarely true**	**Some-times true**	**Often true**	**True, nearly all the time**
1. I am able to adapt when changes occur.	☐	☐	☐	☐	☐
2. I have at least one close and secure relationship that helps me when I am stressed.	☐	☐	☐	☐	☐
3. When there are no clear solutions to my problems, sometimes fate or God can help.	☐	☐	☐	☐	☐
4. I can deal with whatever comes my way.	☐	☐	☐	☐	☐
5. Past successes give me confidence in dealing with new challenges and difficulties.	☐	☐	☐	☐	☐
6. I try to see the humorous side of things when I am faced with problems.	☐	☐	☐	☐	☐
7. Having to cope with stress can make me stronger.	☐	☐	☐	☐	☐
8. I tend to bounce back after illness, injury, or other hardships.	☐	☐	☐	☐	☐
9. Good or bad, I believe that most things happen for a reason.	☐	☐	☐	☐	☐
10. I give my best effort no matter what the outcome may be.	☐	☐	☐	☐	☐
11. I believe I can achieve my goals, even if there are obstacles.	☐	☐	☐	☐	☐

	Not true at all	Rarely true	Some-times true	Often true	True, nearly all the time
12. Even when things look hopeless, I don't give up.	☐	☐	☐	☐	☐
13. During times of stress/crisis, I know where to turn for help.	☐	☐	☐	☐	☐
14. Under pressure, I stay focused and think clearly.	☐	☐	☐	☐	☐
15. I prefer to take the lead in solving problems rather than letting others make all the decisions.	☐	☐	☐	☐	☐
16. I am not easily discouraged by failure.	☐	☐	☐	☐	☐
17. I think of myself as a strong person when dealing with life's challenges and difficulties.	☐	☐	☐	☐	☐
18. I can make unpopular or difficult decisions that affect other people, if it is necessary.	☐	☐	☐	☐	☐
19. I am able to handle unpleasant or painful feelings like sadness, fear and anger.	☐	☐	☐	☐	☐
20. In dealing with life's problems, sometimes you have to act on a hunch without knowing why.	☐	☐	☐	☐	☐
21. I have a strong sense of purpose in life.	☐	☐	☐	☐	☐
22. I feel in control of my life.	☐	☐	☐	☐	☐
23. I like challenges	☐	☐	☐	☐	☐
24. I work to attain my goals no matter what roadblocks I encounter along the way.	☐	☐	☐	☐	☐
25. I take pride in my achievements.	☐	☐	☐	☐	☐

Section A: Living Life

A-2 We are interested in how much you agree with the following statements. Read each statement carefully. Indicate how much you agree with each statement.

	Strongly disagree	Disagree somewhat	Disagree slightly	Agree slightly	Agree somewhat	Strongly agree
1. I tend to be influenced by people with strong opinions.	☐	☐	☐	☐	☐	☐
2. I have confidence in my opinions, even if they are contrary to the general consensus.	☐	☐	☐	☐	☐	☐
3. I judge myself by what I think is important, not by the values of what others think is important.	☐	☐	☐	☐	☐	☐
4. In general, I feel I am in charge of the situation in which I live.	☐	☐	☐	☐	☐	☐
5. The demands of everyday life often get me down.	☐	☐	☐	☐	☐	☐
6. I am quite good at managing the many responsibilities of my daily life.	☐	☐	☐	☐	☐	☐
7. I think it is important to have new experiences that challenge how you think about yourself and the world.	☐	☐	☐	☐	☐	☐
8. For me, life has been a continuous process of learning, changing and growth.	☐	☐	☐	☐	☐	☐

	Strongly disagree	Disagree somewhat	Disagree slightly	Agree slightly	Agree somewhat	Strongly agree
9. I gave up trying to make big improvements or changes in my life a long time ago.	☐	☐	☐	☐	☐	☐
10. Maintaining close relationships has been difficult and frustrating for me.	☐	☐	☐	☐	☐	☐
11. People would describe me as a giving person, willing to share my time with others.	☐	☐	☐	☐	☐	☐
12. I have not experienced many warm and trusting relationships with others.	☐	☐	☐	☐	☐	☐
13. I live life one day at a time and don’t really think about the future.	☐	☐	☐	☐	☐	☐
14. Some people wander aimlessly through life, but I am not one of them.	☐	☐	☐	☐	☐	☐
15. I sometimes feel as if I’ve done all there is to do in life.	☐	☐	☐	☐	☐	☐
16. When I look at the story of my life, I am pleased with how things have turned out.	☐	☐	☐	☐	☐	☐
17. I like most aspects of my personality.	☐	☐	☐	☐	☐	☐
18. In many ways, I feel disappointed about my achievement in life.	☐	☐	☐	☐	☐	☐

Section B: Managing Life

B-1 Think of situation when you have been bothered or stressed because of your illness. Below you will find a list of ways in which people may deal with their feelings in these situations. Please tell us, how often you ***usually*** do these things or have these kind of thoughts related to your illness.

	Never	**Rarely**	**Some-times**	**Often**	**Always**
1. I am able to manage my illness.	☐	☐	☐	☐	☐
2. I have got used to my illness.	☐	☐	☐	☐	☐
3. I cope well with my illness.	☐	☐	☐	☐	☐
4. I accept my illness.	☐	☐	☐	☐	☐
5. I take my illness easy.	☐	☐	☐	☐	☐
6. I face my situation with humor.	☐	☐	☐	☐	☐
7. I try to ignore my illness.	☐	☐	☐	☐	☐
8. I pretend to be all right.	☐	☐	☐	☐	☐
9. I try to forget my illness.	☐	☐	☐	☐	☐
10. I think about my illness.	☐	☐	☐	☐	☐
11. I believe that faith in God helps me.	☐	☐	☐	☐	☐
12. I pray that my illness will go away.	☐	☐	☐	☐	☐
13. I learn as much as possible about my illness.	☐	☐	☐	☐	☐
14. I tell myself that even famous people have illnesses.	☐	☐	☐	☐	☐
15. I think of worse situations.	☐	☐	☐	☐	☐
16. I don’t care about my illness.	☐	☐	☐	☐	☐
17. I think my illness is no big deal.	☐	☐	☐	☐	☐

	Never	Rarely	Some-times	Often	Always
18. I think my illness is not so serious.	☐	☐	☐	☐	☐
19. I forget about my illness.	☐	☐	☐	☐	☐
20. I cry.	☐	☐	☐	☐	☐
21. I am frustrated.	☐	☐	☐	☐	☐
22. I am angry.	☐	☐	☐	☐	☐
23. I wake up at night and think of terrible things.	☐	☐	☐	☐	☐
24. I am ashamed of being ill.	☐	☐	☐	☐	☐
25. I think it is unfair that I am ill.	☐	☐	☐	☐	☐
26. I want to stop having my illness.	☐	☐	☐	☐	☐
27. I hope that my illness disappears.	☐	☐	☐	☐	☐
28. I wish I were healthy.	☐	☐	☐	☐	☐
	Very Well				**Not well at all**
29. Overall, how well do you think you cope with your illness?	☐	☐	☐	☐	☐

B-2 We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement, from **very strongly disagree to very strongly agree**.

	Very strongly disagree	**Strongly disagree**	**Mildly disagree**	**Neutral**	**Mildly agree**	**Strongly agree**	**Very strongly agree**
1. There is a special person who is around when I am in need.	☐	☐	☐	☐	☐	☐	☐
2. There is a special person with who I can share my joys and sorrows.	☐	☐	☐	☐	☐	☐	☐
3. My family really tries to help me.	☐	☐	☐	☐	☐	☐	☐
4. I get the emotional help and support I need from my family.	☐	☐	☐	☐	☐	☐	☐
5. I have a special person who is a real source of comfort to me.	☐	☐	☐	☐	☐	☐	☐
6. My friends really try to help me.	☐	☐	☐	☐	☐	☐	☐
7. I can count on my friends when things go wrong.	☐	☐	☐	☐	☐	☐	☐
8. I can talk about my problems with my family.	☐	☐	☐	☐	☐	☐	☐
9. I have friends with whom I can share my joys and sorrows.	☐	☐	☐	☐	☐	☐	☐
10. There is a special person in my life who cares about my feelings.	☐	☐	☐	☐	☐	☐	☐
11. My family is willing to help me make decisions.	☐	☐	☐	☐	☐	☐	☐
12. I can talk about my problems with my friends.	☐	☐	☐	☐	☐	☐	☐

B-3 Read each item carefully. Using the scale shown below, from **Definitely False to Definitely True**, please select the answer that best describes **YOU** and put that number in the blank provided.

	Definitely false	Mostly false	Somewhat false	Slightly false	Slightly true	Somewhat true	Mostly true	Definitely true
1. I can think of many ways to get out of a jam.	☐	☐	☐	☐	☐	☐	☐	☐
2. I energetically pursue my goals.	☐	☐	☐	☐	☐	☐	☐	☐
3. I feel tired most of the time.	☐	☐	☐	☐	☐	☐	☐	☐
4. There are lots of ways around any problem.	☐	☐	☐	☐	☐	☐	☐	☐
5. I am easily downed in an argument.	☐	☐	☐	☐	☐	☐	☐	☐
6. I can think of many ways to get the things in life that are important to me.	☐	☐	☐	☐	☐	☐	☐	☐
7. I worry about my health.	☐	☐	☐	☐	☐	☐	☐	☐
8. Even when others get discouraged, I know I can find a way to solve the problem.	☐	☐	☐	☐	☐	☐	☐	☐
9. My past experiences have prepared me well for my future.	☐	☐	☐	☐	☐	☐	☐	☐
10. I've been pretty successful in life.	☐	☐	☐	☐	☐	☐	☐	☐
11. I usually find myself worrying about something.	☐	☐	☐	☐	☐	☐	☐	☐
12. I meet the goals that I set for myself.	☐	☐	☐	☐	☐	☐	☐	☐

Section C: Experiencing Life

C-1 Emotions play an important part in most illnesses. Read each item and **check** the reply which comes closest to how you have been feeling in the **past week**. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or "wound up":

☐ Most of the time
☐ A lot of the time
☐ From time to time, occasionally
☐ Not at all

2. I still enjoy the things I used to enjoy:

☐ Definitely as much
☐ Not quite so much
☐ Only a little
☐ Hardly at all

3. I get sort of a frightened feeling as if something awful is about to happen:

☐ Very definitely and quite badly
☐ Yes, but not too badly
☐ A little, but it doesn't worry me
☐ Not at all

4. I can laugh and see the funny side of things:

☐ As much as I always could
☐ Not quite so much now
☐ Definitely not so much now
☐ Not at all

5. Worrying thoughts go through my mind:

☐ A great deal of the time
☐ A lot of the time
☐ From time to time but not too often
☐ Only occasionally

6. I feel cheerful:

☐ Not at all
☐ Not often
☐ Sometimes
☐ Most of the time

7. I can sit at ease and feel relaxed:

☐ Definitely
☐ Usually
☐ Not often
☐ Not at all

8. I feel as if I am slowed down:
☐ Nearly all the time
☐ Very often
☐ Sometimes
☐ Not at all

9. I get a sort of frightened feeling like “butterflies” in the stomach:
☐ Not at all
☐ Occasionally
☐ Quite often
☐ Very often

10. I have lost interest in my appearance:
☐ Definitely
☐ I don’t take so much care as I should
☐ I may not take quite as much care
☐ I take just as much care as ever

11. I feel restless as if I have to be on the move:
☐ Very much indeed
☐ Quite a lot
☐ Not very much
☐ Not at all

12. I look forward with enjoyment to things:
☐ As much as ever I did
☐ Rather less than I used to
☐ Definitely less than I used to
☐ Hardly at all

13. I get sudden feelings of panic:
☐ Very often indeed
☐ Quite often
☐ Not very often
☐ Not at all

14. I can enjoy a good book or radio or TV program:
☐ Often
☐ Sometimes
☐ Not often
☐ Very seldom

C-2 Please indicate how often you felt or thought a certain way **in the last month**.	**Never**	**Almost never**	**Some-times**	**Fairly often**	**Very often**
1. How often have you had too many things to do?	☐	☐	☐	☐	☐
2. How often have you felt you were in a hurry?	☐	☐	☐	☐	☐
3. How often have you felt under pressure from deadlines?	☐	☐	☐	☐	☐
4. In the last month, how often have you found yourself in situations of conflict?	☐	☐	☐	☐	☐
5. How often have you felt you were doing things because you had to not because you wanted to?	☐	☐	☐	☐	☐
6. How often have you felt criticized or judged?	☐	☐	☐	☐	☐
7. How often have you felt difficulties were piling up so high that you could not overcome them?	☐	☐	☐	☐	☐
8. How often have you felt that you were on top of things?	☐	☐	☐	☐	☐
9. How often have you had too many worries?	☐	☐	☐	☐	☐

Section D: Impact of Your MS

D-1 For each of the following areas, please choose the option that **BEST** describes your current level of functioning.

1. Vision

☐ Able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street, without glasses or contact lenses.

☐ Able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street, but with glasses.

☐ Able to read ordinary newsprint with or without glasses but unable to recognize a friend on the other side of the street, even with glasses.

☐ Able to recognize a friend on the other side of the street with or without glasses but unable to read ordinary newsprint, even with glasses.

☐ Unable to read ordinary newsprint and unable to recognize a friend on the other side of the street, even with glasses.

☐ Unable to see at all.

2. Hearing

☐ Able to hear what is said in a group conversation with at least three other people, without a hearing aid.

☐ Able to hear what is said in a conversation with one other person in a quiet room without a hearing aid, but requires a hearing aid to hear what is said in a group conversation with at least three other people.

☐ Able to hear what is said in a conversation with one other person in a quiet room with a hearing aid, and able to hear what is said in a group conversation with at least three other people, with a hearing aid.

☐ Able to hear what is said in a conversation with one other person in a quiet room, without a hearing aid, but unable to hear what is said in a group conversation with at least three other people even with a hearing aid.

☐ Able to hear what is said in a conversation with one other person in a quiet room with a hearing aid, but unable to hear what is said in a group conversation with at least three other people even with a hearing aid.

☐ Unable to hear at all.

3. Speech

☐ Able to be understood completely when speaking with strangers or people who know me well.

☐ Able to be understood partially when speaking with strangers but able to be understood completely when speaking with people who know me well.

☐ Able to be understood partially when speaking with strangers or people who know me well.

☐ Unable to be understood when speaking with strangers but able to be understood partially by people who know me well.

☐ Unable to be understood when speaking to other people (or unable to speak at all).

4. Ambulation

☐ Able to walk around the neighbourhood without difficulty, and without walking equipment.

☐ Able to walk around the neighbourhood with difficulty, but does not require walking equipment or the help of another person.

☐ Able to walk around the neighbourhood with walking equipment, but without the help of another person.

☐ Able to walk only short distances with walking equipment, and requires a wheelchair to get around the neighbourhood.

☐ Unable to walk alone, even with walking equipment. Able to walk short distances with the help of another person, and requires a wheelchair to get around the neighbourhood.

☐ Cannot walk at all.

5. Pain

☐ Free of pain and discomfort.

☐ Mild to moderate pain that prevents no activities.

☐ Moderate pain that prevents a few activities.

☐ Moderate to severe pain that prevents some activities.

☐ Severe pain that prevents most activities.

6. Dexterity

☐ Full use of two hands and ten fingers.

☐ Limitations in the use of hands or fingers, but does not require special tools or help of another person.

☐ Limitations in the use of hands or fingers, is independent with use of special tools (does not require the help of another person).

☐ Limitations in the use of hands or fingers, requires the help of another person for some tasks (not independent even with the use of special tools).

☐ Limitations in the use of hands or fingers, requires the help of another person for most tasks (not independent even with the use of special tools).

☐ Limitations in the use of hands or finders, requires the help of another person for all tasks (not independent even with the use of special tools).

7. Emotion

☐ Happy and interested in life.

☐ Somewhat happy.

☐ Somewhat unhappy.

☐ Very unhappy.

☐ So unhappy that life is not worthwhile.

8. Cognition

☐ Able to remember most things, think clearly and solve day to day problems.

☐ Able to remember most things, but have a little difficulty when trying to think and solve day to day problems.

☐ Somewhat forgetful, but able to think clearly and solve day to day problems.

☐ Somewhat forgetful, and have a little difficulty when trying to think or solve day to day problems.

☐ Very forgetful, and have great difficulty when trying to think or solve day to day problems.

☐ Unable to remember anything at all, and unable to think or solve day to day problems.

D-2 Below is a list of statements that describe how fatigue may cause problems in people’s lives. Please read each statement carefully and check the box that indicates **BEST** how much of a problem fatigue has been for you **TODAY**.

Because of fatigue…	**No problem**	**Small problem**	**Moderate problem**	**Big problem**	**Extreme problem**
1. I feel less alert.	☐	☐	☐	☐	☐
2. I have to reduce my workload or responsibilities.	☐	☐	☐	☐	☐
3. I am less motivated to do anything that requires physical effort.	☐	☐	☐	☐	☐
4. I have trouble maintaining physical effort for long periods.	☐	☐	☐	☐	☐
5. I find it difficult to make decisions.	☐	☐	☐	☐	☐
6. I am less able to finish tasks that require thinking.	☐	☐	☐	☐	☐
7. I feel slowed down in my thinking.	☐	☐	☐	☐	☐
8. I have to limit my physical activities.	☐	☐	☐	☐	☐

Section E: About You

1. **Gender:** ☐ Female ☐ Male

2. **Date of Birth:** MM / DD / YY

3. **Age:** ☐☐

4. **Marital Status: (check only one)**
   - ☐ Married / Common law / domestic partner
   - ☐ Divorced / separated
   - ☐ Widowed
   - ☐ Single / never married
   - ☐ Other: ____

5. **Current living arrangements: (check all that apply)**
   - ☐ Alone
   - ☐ With spouse / common-law / domestic partner
   - ☐ With immediate family (i.e.; adult children, parents)
   - ☐ With relatives other than spouse/partner, children, parents
   - ☐ With non-relatives who are not paid caregivers
   - ☐ With non-relatives who are paid caregivers
   - ☐ Other: ____

6. **Current living situation: (check only one)**
   - ☐ Independent household (any house, condo, apartment – owned or rented)
   - ☐ Assisted living
   - ☐ Group homes
   - ☐ Long term care center (nursing home)
   - ☐ Other: ____

7. **In the past 12 months, how difficult or easy was it for you and your household to meet your overall needs in terms of transportation, housing, food, clothing and other necessary expenses? Was it…?**
   - ☐ Very difficult
   - ☐ Difficult
   - ☐ Easy
   - ☐ Very easy
   - ☐ Don’t know

8. In the past 12 months, have you and your household experienced significant financial difficulty because of the multiple sclerosis?

☐ Yes, sometimes
☐ Yes, often
☐ No
☐ Don`t know

9. Primary source of emotional support (i.e.; offering of empathy, concern, acceptance): (check only one)

☐ Spouse / common-law / domestic partner
☐ Immediate Family (i.e.; children, parents)
☐ Friends / Extended Family / Neighbours
☐ Health care providers
☐ Other persons with MS (e.g.; MS support group)
☐ Other: ____

10. Primary source of tangible support (i.e.; practical, concrete help with finances, chores etc.): (check only one)

☐ Spouse / common-law / domestic partner
☐ Immediate Family (i.e.; children, parents)
☐ Friends / Extended Family / Neighbours
☐ Health care providers
☐ Other persons with MS (e.g.; MS support group)
☐ Other: ____

11. Primary source of informational support (i.e.; advice, guidance, suggestions): (check only one)

☐ Spouse / common-law / domestic partner
☐ Immediate Family (i.e.; children, parents)
☐ Friends / Extended Family / Neighbours
☐ Health care providers
☐ Other persons with MS (e.g.; MS support group)
☐ Other: ____

12. Primary source of companionship (i.e.; sense of belonging, shared activities): (check only one)

☐ Spouse / common-law / domestic partner
☐ Immediate family (i.e.; children, parents)
☐ Friends / Extended Family / Neighbours
☐ Health care providers
☐ Other persons with MS (e.g.; MS support group)
☐ Other: ____

13. Education level:

☐ No formal education
☐ Some elementary, junior high or high school education
☐ High school graduate
☐ Some post-secondary education
☐ Apprenticeship, trade or technical certificate or diploma
☐ Undergraduate/professional post-secondary degree / diploma
☐ Graduate/professional degree

14. Employment: (check ALL that apply)

☐ Full-time (including self-employed full-time)
☐ Part-time (including self-employed part-time)
☐ Homemaker
☐ Student – full-time
☐ Student – part-time
☐ Maternity / Paternity / Compassionate leave
☐ Short-term disability leave, due to MS
☐ Short-term disability leave, not due to MS
☐ Long-term disability leave, due to MS
☐ Long-term disability leave, not due to MS
☐ Retired, due to MS
☐ Retired, not due to MS
☐ Unemployed, due to MS
☐ Unemployed, not due to MS
☐ Other: ____

15. Other Diseases

Has a doctor ever told you that you have any of the following conditions?

For each condition, please mark yes or no. If you do *not* have the problem, skip to the next. If you *do* have the problem: - Please write in the year you were diagnosed. - Please indicate if you receive a medicine or some type of treatment for the problem.	**No**	**Yes**	**If YES: Year Diagnosed**	**If YES: Currently treated?**	
				No	**Yes**
High cholesterol (hyperlipidemia)	☐	☐		☐	☐
High blood pressure (hypertension)	☐	☐		☐	☐
Heart trouble (such as angina, congestive heart failure, or coronary artery disease)	☐	☐		☐	☐
Diabetes	☐	☐		☐	☐
Thyroid disease (such as Graves' disease, Hashimoto's thyroiditis, *not* thyroid cancer)	☐	☐		☐	☐
Inflammatory bowel disease (Crohn's disease, ulcerative colitis)	☐	☐		☐	☐
Epilepsy (seizure disorder)	☐	☐		☐	☐
Depression	☐	☐		☐	☐
Anxiety disorder	☐	☐		☐	☐
Other: ____	☐	☐		☐	☐

Section F: About Your MS

16. Disease duration

a. How old were you when you were first diagnosed with MS? ☐☐

b. When you think back, how old were you when you first experienced symptoms that you believe were from MS? ☐☐

17. Relapse rate

I have relapsing-remitting MS – If yes, please answer the following question. If no, please go to the next question.

Definition of a relapse or exacerbation of MS: Development of new symptoms or worsening of old symptoms that last longer than 48 hours. In a relapse or exacerbation, MS symptoms generally worsen over a period of days to several weeks. They then improve partially or completely over several weeks or months. A relapse can be associated with several different symptoms getting worse at the same time. **For our purposes here, the change in symptoms cannot be due to heat or illness (i.e., flu, cold or urinary tract infection) to be called a relapse or exacerbation**.

c. Based on the definition above, have you had a relapse in the last 6 months?

☐ Yes, how many? ___________
☐ No
☐ Unsure

d. Have you had any relapses within the last year?

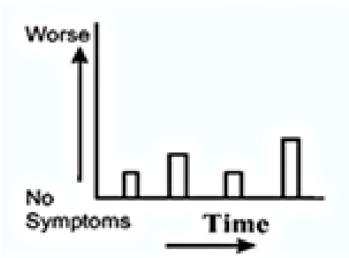
☐ Yes, how many? ___________
☐ No
☐ Unsure

e. Within the last 2 years?

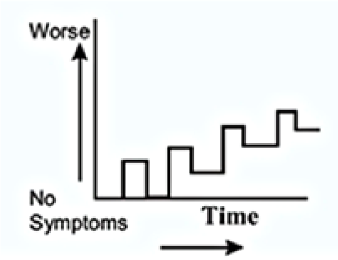
☐ Yes, how many? ___________
☐ No
☐ Unsure

18. Type of MS:

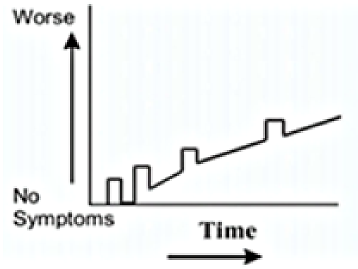
Please select one of the following examples that **BEST** describes the **OVERALL** course of your MS over time.



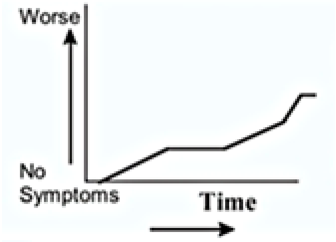
☐ a. Attacks (exacerbations, relapses) come on over a few hours or days, last from one day to several weeks, but one they are over, you feel the same as you always have.



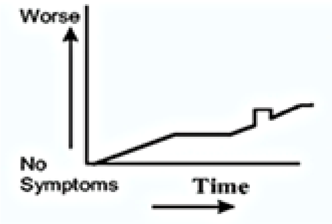
☐ b. Attacks (exacerbations, relapses) come on over a few hours or days, last from one day to several weeks. After some attacks, your symptoms are **worse** than before. **The symptoms that remain after the attacks are stable until a new attack occurs.**



☐ c. At the **start** of the disease, attacks (exacerbations, relapses) occur. You may feel your symptoms get worse because of these attacks. Then even **between** the attacks, you feel you are getting worse. In some cases, attacks **cease**, yet your symptoms continued to worsen.



☐ d. Symptoms worsen from the beginning. Your symptoms may be stable for a time, gradually worsen, or deteriorate rapidly, but **attacks** (exacerbations, relapses) **have never occurred**.



☐ e. Symptoms gradually worsen from the beginning. You may be stable for a time at the beginning, or may deteriorate rapidly. **Attacks** (exacerbations, relapses) **did not occur at the start, but may occur later in the course of the disease.**

19. Patient-Determined Disease Steps

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

☐ **Normal:** I may have some mild symptoms, mostly sensory due to MS but they do not limit my activity. If I do have an attack, I return to normal when the attack has passed.

☐ **Mild Disability:** I have some noticeable symptoms from my MS but they are minor and have only a small effect on my lifestyle.

☐ **Moderate Disability:** I don't have any limitations in my walking ability. However, I do have significant problems due to MS that limit daily activities in other ways.

☐ **Gait Disability:** MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need a cane or other assistance to walk, but I might need some assistance during an attack.

☐ **Early Cane:** I use a cane or a single crutch or some other form of support (such as touching a wall or leaning on someone's arm) for walking all the time or part of the time, especially when walking outside. I think I can walk 25 feet in 20 seconds without a cane or crutch. I always need some assistance (cane or crutch) if I want to walk as far as 3 blocks.

☐ **Late Cane:** To be able to walk 25 feet, I have a have a cane, crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances.

☐ **Bilateral Support:** To be able to walk as far as 25 feet I must have 2 canes or crutches or a walker. I may use a scooter or wheelchair for longer distances.

☐ **Wheelchair / Scooter:** My main form of mobility is a wheelchair. I may be able to stand and/or take one or two steps, but I can't walk 25 feet, even with crutches or a walker.

☐ **Bedridden:** Unable to sit in a wheelchair for more than one hour.

APPENDIX F – Qualitative Study Interview Guide

- Describe a time when you were able to successfully adapt to a home or work or personal situation with having MS.
- Can you tell me about a time when you were not able to successfully adapt?
- Describe a time when you felt you were coping well with MS. What helped? What got in the way?
- Describe a time when you felt you were not coping well? What helped? What got in the way?
- Can you describe at time when you felt you were well supported?
- Have you ever felt unsupported? Can you tell me about that experience?
- Have you ever felt all alone? Can you tell me about that experience?
- Can you tell me about a time when you felt healthy and well, in spite of having MS?
- Have you ever felt a sense of being unwell mentally, emotionally, socially? Can you tell me about that experience?
- Can you tell me about a time that you felt particularly anxious or worried. What was that experience like?
- Can you describe a time when you felt you were handling stress well? What helped? What got in the way? Can you describe a time when you felt you weren't handling stress well? What helped? What got in the way?
- Can you think of a time when you felt you had gotten the better of your MS? What was that experience like?
- Can you think of time when you felt your MS had gotten the better of you? What was that experience like?
- Can you remember a time when you had to "pick yourself up" and carry on? Can you tell me about that experience?