

**THE EFFECTS OF RESILIENCE AND DISABILITY ON PARTICIPATION AND  
HEALTH-RELATED QUALITY OF LIFE AMONG OLDER CANADIANS WITH  
MULTIPLE SCLEROSIS**

by

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## **ABSTRACT**

This study investigated the characteristics older individuals with Multiple Sclerosis (MS). The focus was on examining high and low levels of resilience as well as the effect of resilience on health-related quality of life (HRQOL) and participation. Standardized measures were completed by 743 Canadian 55 years of age and older with MS. It was found that individuals with high levels of resilience were significantly older, reported lower disability, less impact of MS, and better mental health. The high resilience group reported being more physically active, participated more frequently in daily activities, had greater social support and perceived health, and were less financially stable than individuals with low levels of resilience. Resilience accounted for a significant proportion of variance in perceived health status (7.2%) and impact of MS (5.7%) considered as measures of HRQOL, and participation (3.1%). These findings inform future strategies to improve the lives of individuals aging with MS.

## **DEDICATION**

To each and every person living with Multiple Sclerosis.

"The greatest discovery of my generation is that a human being can alter his life by altering his  
attitudes of mind"

- William James

## **ACKNOWLEDGEMENTS**

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## **List of Abbreviations**

MS: Multiple Sclerosis  
MSSC: Multiple Sclerosis Society of Canada  
QOL: Quality of Life  
HRQOL: Health-related Quality of Life  
PTG: Post-traumatic Growth  
IADL/ADL: (instrumental) activities of daily living  
RRMS: Relapse-Remitting Multiple Sclerosis  
SPMS: Secondary-Progressive Multiple Sclerosis  
PPMS: Primary-Progressive Multiple Sclerosis  
RS-14: 14-item Resilience Scale  
RS: Resilience Scale  
BI: Barthel Index  
MSIS-29: Multiple Sclerosis Impact Scale  
VAS: Visual analogue scale  
FAI: Frenchay Activities Index  
SLIQ: Simple Lifestyle Indicator Questionnaire  
HADS: Hospital Anxiety and Depression Scale  
PRQ-2000: The Personal Resource Questionnaire  
ANOVA: Analysis of Variance

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## Chapter One

### Introduction

Multiple Sclerosis (MS) is a progressive neurological disease caused by demyelination of the central nervous system typically diagnosed between the ages of 15 to 40 (Multiple Sclerosis Society of Canada (MSSC), 2015). It is characterized by uncertain and unpredictable relapsing and remitting episodes causing symptoms such as vision problems, lack of coordination, extreme fatigue, abnormal bodily sensations including tingling and weakness, and cognitive impairment, and affects three times as many women than men (MSSC, 2015). The course of the disease tends to become chronically progressive about 15 years after diagnosis with most individuals becoming dependent on mobility aids after about 20 years (Ploughman et al., 2012b). As people with MS get older, they must balance the health effects of aging along with the physical and psychological adjustments that come with managing a chronic disease (Ploughman et al., 2012a; Rimmer, 2005). The physical and cognitive symptoms of MS not only affect individuals' mobility and day-to-day functioning but also impacts their life satisfaction and well-being. These symptoms also have a profound effect on overall quality of life (QOL; Montel & Bungener, 2007), referring to the individuals' assessment of how his/her health affects his/her ability to perform activities and participate in roles that he/she values (EuroQOL Group, 1990). Despite these challenges, many individuals have learned to adapt to life with MS and live well into their seventies and beyond (Finlayson, van Denend, & Hudson, 2004; Ploughman et al., 2012b).

The 2012 Canadian Community Health Survey estimates there are just over 93 530 Canadians living with MS (Statistics Canada, 2010). With approximately 27.7% of the

population 55 years of age or older (Statistics Canada, 2012), there could be upwards of 25 000 people living with this disease in this age bracket (Ploughman et al., 2014). Considering the number of older individuals who are living with MS, relatively few have been asked about their experiences living with MS and health-related concerns (Finlayson, van Denend, & Hudson, 2004; Ploughman et al., 2012a; Ploughman et al., 2012b). Current disease-modifying drugs may help reduce the frequency of MS attacks and rate of disability accumulation (Ploughman et al., 2012) but psychological factors like resilience or a person's attitude towards their disease may have a greater impact on their daily functioning and health-related QOL (HRQOL) than these biological markers of disease progression. Thus, the current study investigated whether older individuals with MS with high levels of resilience differ from those with low levels of resilience and examined the effect of resilience on the relationship between disability and health-related quality of life (HRQOL), and participation in daily activities.

This thesis is based on a unique dataset of 743 older people with MS. Taking advantage of the opportunity to learn from an aging MS population, the thesis is presented in a traditional style consisting of four chapters. The first chapter places the research in context. The concept of resilience is explained along with what factors may be related to resilience and healthy aging individuals with MS, and how resilience relates to disability, participation in daily activities, and QOL. The first chapter concludes with the rationale for the research project. The second chapter outlines the methods of the study, which explore the differences between participants with high and low levels of resilience and determines how resilience impacts participation and QOL among this older group. The third chapter outlines the results of the study and the final chapter provides a thorough discussion of how this thesis contributes to new knowledge as well as considerations

for future research. The Wilson and Cleary Model for Health-Related Quality Life (Wilson & Cleary, 1995) was used to guide this project (see Appendix A).

## **Resilience**

**The concept of resilience.** Resilience refers to the ability to achieve, retain, or regain a level of physical or emotional health after illness or loss (Resnick & Inguito, 2011) and has been described as successful coping or 'bouncing back' in spite of substantial adversity (Rutter, 1985; Wagnild, 2003; Wagnild & Collins, 2009; Wagnild and Young, 1990). The concept of resilience has become widely researched in the mental health field (Damásio, Borsa, da Silva, 2011; Oshio, Kaneko, Nagamine, & Nakays, 2003) and gained widespread interest across various disciplines because of its role in the process of overcoming and adapting to negative circumstances. Resilience is comprised of five interrelated components including: equanimity, perseverance, self-reliance, meaningfulness and existential aloneness. First, equanimity refers to a balanced perspective of life, having learned to avoid extreme responses to stress, and being able to 'take what comes' (Wagnild, 2013; Wagnild & Young, 1993). Perseverance describes the act of persistence or "a willingness to continue to struggle to reconstruct one's life" (p. 167) in spite of adversity or setbacks (Wagnild & Young, 1993). Self-reliance describes a belief in one's own strengths and capabilities while meaningfulness refers to having a sense of purpose in life (Wagnild & Collins, 2009; Wagnild & Young, 1993). Meaningfulness has been noted as possibly the most important characteristic of resilience because it provides the foundation for the other four components. Finally, existential aloneness refers to the realization that every individual's life path is unique and while some experiences are shared, others are faced alone (Wagnild & Collins, 2009; Wagnild & Young, 1993).

Wagnild and Young (1993) define resilience as "a personality characteristic that moderates the negative effect of stress and promotes adaptation" (p. 165). The concept of resilience as a stable personality trait as opposed to a fluid dynamic process that encompasses positive adaptation in the context of trauma or adversity (Luthar & Cicchetti, 2000) has been highly debated throughout the literature. Rutter (2007), for example, argues that resilience "is not and cannot be a personality trait" (p. 205). Rutter (2007) along with Luthar and Cicchetti (2000), Masten (1999), and Masten and Wright (2010), believe that individuals can only become resilient in the presence of adversity which varies from one situation to the next. This suggests that resilience can develop at any point over the lifespan (Jacelon, 1997). Wagnild (2003) admits that although resilience may be an innate characteristic that each of us possess to some degree, it can be enhanced or diminished depending on life circumstance. She explains, "how one moves from vulnerability (less resilience) to more resilience is itself a process, but the character of resilience, however fluid, is not a process" (p. 43). Therefore, resilience as a component of an individual's personality is likely to change over time due to life events and challenges that shape our experiences (Resnick & Inguito, 2011).

**Related terms and constructs.** Resilience overlaps with other psychological terms and constructs described in the literature. One such term is ego resilience, a construct that refers to a set of personal characteristics of an individual reflecting general resourcefulness, sturdiness of character, and flexibility in response to environmental demands or life stressors (Block & Block, 1980). Ego resiliency, like Wagnild and Young's (1993) definition of resilience, refers to a personality trait as opposed to a dynamic developmental process and does not pre-suppose exposure to adversity (Luthar, Cicchetti, & Becker, 2000). Hardiness is another personality construct associated with resilience that describes a specific set of attitudes (Stewart & Yuen,

2011) towards control (a tendency to act and feel as if one has influence over external forces), commitment (a tendency to find purpose and meaning in life's activities), and challenge (a belief that change is normal and an opportunity for growth) (Kobasa, Maddi, & Kahn, 1982; Skodol, 2010). Both hardiness and resilience pertain to endurance of significant adversity, however, only resilience results in improved or enhanced adaptation (Earvolino-Ramirez, 2007).

In their early study on successfully adjusted older women, Wagnild and Young (1990) noted that resilience describes individuals who display emotional stamina or "courage and adaptability in the wake of life's misfortunes" (p. 254). In 1988, Druss and Douglas found that resilient individuals "were better able to focus on positive aspects of their difficult situation" when faced with adversity. As a result, this study argues that individuals who are resilient and optimistic towards the future despite having a diagnosis of MS have adopted a 'survivor attitude'. The term survivor attitude was adapted from a book entitled *'100 Perks of Having Cancer'* by Florence Strang (Strang & Gonzalez, 2013). In this book, Strang discusses adopting a survivor attitude in her battle with stage three breast cancer by focusing on the positive changes that occurred in her life (i.e., body, mind, and spirit) instead of dwelling on what cancer had taken away from her. She explains that while no one chooses to get cancer or any form of chronic illness, each person living with a disease has a choice in how they are going to cope with it (Strang & Gonzalez, 2013). Emphasizing this statement, she writes, "I believe that my quality of life is not so much determined by the events of my life, but rather by the attitude that I bring to it" (Strang & Gonzalez, 2013, p. 346).

After reading Strang and Gonzalez's (2013) book, this author became very passionate about the concept of a survivor attitude, which sparked an interest in linking the concept to one's attitude towards living with MS. Given the chronic nature of MS and lack of a cure, this disease

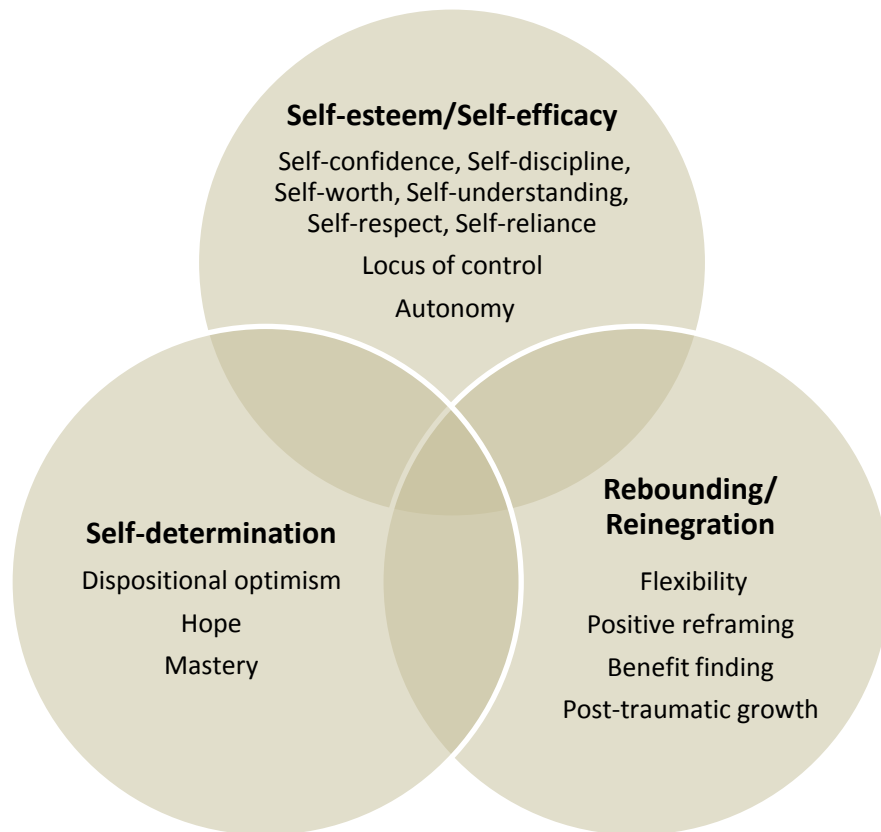
is likely to have a profound impact on the daily functioning and quality of life of individuals with this condition. Research on the effects of adopting a survivor attitude has not been conducted because the term, according to this author's search, does not exist in the medical or psychological literature. Thus, a number of positive psychological terms in the literature were examined in an effort to operationally define survivor attitude for the purposes of this thesis. As a result, resilience was selected as the characteristic that best represented Strang's description of a survivor attitude that could be systematically measured.

Thus, in the context of this study, having a survivor attitude is equated to being resilient. This idea fits nicely with Ong, Bergeman, and Chow's (2010) work, which discuss positive emotions as the basic building block of resilience in adulthood. Having a survivor attitude aligns closely with the characteristic of perseverance, referring to the "determination to keep going despite difficulties, discouragement, and disappointment" (Wagnild, 2013, p. 11). Both of these concepts demonstrate an individual's courageousness and ability to adapt to daily life challenges such as those associated with living with MS. However, unlike resilience, survivor attitude is not is not a measurable construct. Thus, the results of this study pertain only to the effects of resilience.

**What are the attributes of resilience and resilient people?** Earvolino-Ramirez (2007) described a number of defining attributes/characteristics of resilience in a concept analysis conducted on resilience. These attributes served as a foundation for the following sections that describe various characteristics associated with resilient individuals. See Figure 1 for a diagram summarizing these attributes and related concepts.



Figure 1. Attributes and concepts related to resilience.



*Self-esteem and self-efficacy.* The first attributes reviewed by Earvolino-Ramirez (2007) were self-esteem and self-efficacy, which are often associated with why some people who face adversity are able to restore a sense of balance in their life and why others are not. Self-esteem relates to an individual's sense of self-worth and self-respect while self-efficacy refers to an individual's belief in their own capacity to manage life's challenges and difficult situations (Skodol, 2010). Skodol (2010) described resilient personalities as being characterized by traits, "that reflect a strong, well-differentiated, and integrated sense of self" (p.113), hence the concepts of self-confidence and self-understanding, which contribute to higher levels of adaptive functioning. Resilient people are also characterized as autonomous and self-reliant because they do not depend on others to meet their needs or solve their problems (Skodol, 2010). Individuals

who possess these qualities are said to have an internal locus of control, a belief that the events in a person's life are for the most part, self-determined or within their control, rather than a product of fate (Skodol, 2010), similar to the control aspect of hardiness described earlier. Adding to these findings, Kralik, van Loon and Visentin's (2006), in their participatory action research study on individuals living with chronic illness, concluded that resilience involves the belief that self-worth transcends physical limitation.

Descriptions of resilient individuals possessing various positive psychological attributes are described in several early writings discussed by Wagnild and Young (1993, 1990). Rutter (1987), for example, described resilient individuals as having self-esteem and strong belief in their self-efficacy while Beardslee (1989), Caplan (1990), Honzik (1984), and Richmond and Beardslee (1988) identified resilience as having self-confidence, self-esteem, self-discipline, and control over one's environment. Incidentally, Beardslee (1989) referred to resilient persons as survivors, an idea that foreshadows the concept of survivor attitude presented here.

***Self-determination.*** Another attribute of resilience described by Earvolino-Ramirez (2007) was self-determination, a feeling that one will overcome barriers and excel regardless of life circumstance. This term also captures the concept of self-worth, in which an individual does not feel overwhelmed by "feelings of hopelessness or extreme challenge based on a strong internal belief that whatever life brings the individual will persevere" (Earvolino-Ramirez, 2007, p. 77). In their investigation of the role of resilience in chronic illness and disability in older adults, Rybarczyk, Emery, Guequierre, Shamaskin, and Behel (2012) identified two additional positive psychological factors underpinning individuals' ability to cope with adversity: dispositional optimism and hope. Dispositional optimism is considered a stable psychological quality or trait related to one's positive expectations for the future (Scheier & Carver, 1987).

Hope can be conceptualized as a construct related to optimism that refers to a positive motivational state in which an individual finds pathways to desired goals and actively takes steps towards achieving them (Dennison et al., 2009; Snyder, Irving, & Anderson, 1991). Dennison, Moss-Morris and Chalder's (2009) review of the psychological correlates of adjustment in patients with MS supports these findings. They described hope, optimism as well as benefit-finding (to be discussed below) as contributing factors to individuals' positive psychology associated with a number of adjustment outcomes, including physical well-being and QOL. Optimism may help older adults focus on taking steps towards improving their situation instead of becoming withdrawn (Rybarczyk et al., 2012).

Similar to Kralik et al.'s (2006) study reviewed earlier, King et al. (2003) conducted a qualitative study on the nature of resilience in people with chronic, non-progressive disabilities. Fifteen participants between the ages of 30 and 50 years old identified factors that helped or hindered them during major turning points in their lives. As King et al. (2003) pointed out, "Turning points were emotionally compelling experiences and realizations that involved meaning acquired through the routes of belonging, doing, or understanding the self or the world" (p. 184). They found traits such as perseverance and determination to be major protective factors in participant's stories. Participants also derived meaning through several protective processes, including replacing a loss with a gain referred to as transcending, and recognizing new things about themselves, referred to as self-understanding, which was mentioned earlier. The process of transcending is similar to the concept of post-traumatic growth (PTG) in which new meaning is derived from adverse life events (Barskova & Oesterreich, 2009; Stewart & Yuen, 2011). The concept of PTG will be discussed below.

Stewart and Yuen (2011) also discovered optimism, mastery, and several of the psychological factors discussed above to be associated with resilience across a variety of diseases among individuals who were physically ill. Mastery is described as an outcome or consequences of resilience as it defines a person who possesses great skill or knowledge (Earvolino-Ramirez et al., 2007). With repeated mastery, individuals acquire a sense of competence and are therefore, better equipped to handle new experiences (Wagnild & Young, 1993).

***Rebounding/reintegration and flexibility.*** Rebounding or reintegration is described as a quality of moving on in life after adversity and insinuates movement in a positive direction (Earvolino-Ramirez et al., 2007). Capturing the idea of moving forward, Rybarczyk et al. (2012) examined positive reframing as a psychological coping technique among older adults with chronic illness and disability. "Positive reframing involves cognitive processes whereby illness factors and associated functional changes are relabelled as less negative or perhaps even as neutral, challenges redefined as manageable, and positive meaning is found in the illness experience" (Rybarczyk et al., 2012, p. 181). Persons living with a chronic disease like MS can choose to view themselves as either a 'victim' or more positively as a 'survivor' (Rybarczyk et al., 2012) much like Florence Strang in her battle with cancer. The ability to reframe one's encounters with illness or disability can have profound positive effects not only on how individuals view themselves (e.g., self-efficacy, self-esteem) and their health behaviours, but also their over life satisfaction (Rybarczyk et al., 2012).

Similar to positive reframing described above, benefit-finding is a specific type of adaptive coping strategy reported by people with MS and various other illnesses (Stewart & Yuen, 2011), in which they positively evaluate their circumstances and report growth as a result

of their experience (Pakenham, 2005; Polk, 1997; Stewart & Yuen, 2011). This has also been referred to as PTG (Barskova & Oesterreich, 2009; Stewart & Yuen, 2011), which will be discussed throughout the remainder of this section. Finding meaning or growth as a result of a traumatic event such as receiving a medical diagnosis or experiencing a relapse implies a step beyond resilience (Stewart & Yuen, 2011). Thus, from a positive psychology perspective, resilience is more than regaining psychological functioning after a stressful experience (Atkinson, Martin, & Rankin, 2009) and more so about the learning process that enables a person to cope with future trauma (Liney & Joseph, 2005).

Instances of PTG or benefit-finding related to living with chronic illnesses have been documented (Milam, 2006) and been shown to predict health and QOL. Benefit-finding has also been linked to better adjustment (Katz, Flasher, Cacciapaglia, & Nelson, 2001) and mental well-being (Sato, Yamazaki, Sakita, & Bryce, 2008) in several different chronic-illness populations. Individuals with MS in Pakenham and Coxs' (2009) study, for example, viewed their disease as a learning experience. Benefit-finding was associated with better adjustment with regard to positive affect, positive states of mind, and lower levels of depression and anxiety. These positive emotions, influenced by dispositional optimism, (Scheier & Carver, 1985) have a significant impact on how individuals with chronic illness confront adversity (Scheier & Carver, 1992).

A large number of studies related to positive change in the face of adversity focus on PTG among individuals with cancer (Connerty & Knott, 2013). While research on PTG in this population is not the focus of this study, a number of the psychological characteristics discussed in this section are applicable to individuals with this serious, potentially life-threatening condition, including finding benefits or 'perks' (Strang & Gonzalez, 2013) of having cancer and

positive reframing, such as labelling oneself as a 'cancer survivor' (Bellizzi & Black, 2007). Barskova and Oesterreich (2009) also discovered the majority of studies on PTG in people living with serious medical conditions demonstrated positive associations between PTG and several person-related attributes, including optimism, self-esteem, and self-efficacy described earlier. These results were found across diverse patients and survivor groups, including patients with MS, cancer, and other chronic health conditions.

Flexibility was another attribute described by Earvolino-Ramirez et al. (2007) that captures the essence of rebounding from adversity and being able to adapt to change when it occurs. Data from participants' email correspondences in Kralik, van Loon and Visentin's (2006) participatory action research study mentioned earlier revealed that resilience was about being able to learn from experience and "create a new sense of personal order from the chaos and disruption brought about by change" (p. 193). This demonstrates that flexibility, as a characteristic of resilience, is an important concept in the transitional process of learning to adapt to life with chronic illness.

Resilience is a multifaceted concept, comprised of psychological qualities and attributes including self-esteem, self-determination, and elements of rebounding and flexibility that are conceptually linked to each other (see Figure 1). Several of these resilience constructs have been applied to the literature on individuals age 55 and older and those with chronic illness or conditions, however, few studies have looked specifically at resilience among individuals this age in an MS population. The present study aims to fill this gap by shedding light onto some of the positive outcomes (e.g. greater participation and HRQOL) associated with resilience among this demographic of persons living with MS.

## **The Role of Resilience in MS**

According to the Wilson Cleary Model frequently used to guide HRQOL research and practice, resilience is considered an individual characteristic that influences a person's functional status such as level of disability, which contributes to their general health perception. This perception informs the individual's overall QOL. Resilience influences all aspects of a person's life including health and lifestyles choices, and participation in daily activities. Individuals with higher levels of resilience might report differences in their level of functioning and HRQOL compared with those with low levels of resilience. This is particularly relevant for persons living with chronic conditions such as MS, which can lead to physical impairment and/or disability. The following text discusses the research examining how resilience impacts a person's life with MS in each of the following areas: level of disability, physical and psychological impact of MS, participation in daily activities, healthy lifestyle habits, social support, mental health, age, gender, education, and income.

Hardy, Concato and Thomas' (2004) study serves as an overview of this section. This group of researchers demonstrated a number of differences observed among individuals 70 years of age and older who experienced stressful life events. They found that being male, having few depressive symptoms and high self-rated health, and regularly participating in (instrumental) activities of daily living (IADL/ADLs) were associated with high levels of resilience. Similarly, Wagnild and Young (1993) found a positive correlation between resilience and self-rated physical health, and a negative correlation with depression in a cohort of community-dwelling older adults when developing and evaluating the Resilience Scale-25 (RS-25). These topic areas will be discussed further below.

**Level of disability and impact of MS.** Manning, Carr, and Lennox (2014) measured changes in participant's ability to perform IADL/ADLs over a period of two years to estimate the impact of resilience on later disability. Participants were a sample of adults age 51 to 98. They found that higher levels of resilience moderated the progression of a new chronic condition to later disability. Higher levels of resilience protected against IADL/ADLs declines that normally occur with aging. Further, Fraser and Polito (2007) discovered that individuals with Relapsing-Remitting Multiple Sclerosis (RRMS) had significantly greater belief in their ability to control and function with their disease (i.e., greater self-efficacy) than those with more progressive forms of MS. About 85% of people are diagnosed with RRMS (MSSC, 2015), characterized by clearly defined unpredictable relapses, at which time the individual experiences new or worsening symptoms. Recovery at this stage is complete or nearly complete between attacks (MSSC, 2015). Over time, distinct relapses and periods of remission become less frequent and the disease progresses steadily, bringing about increased levels of disability. This type of MS is called secondary-progressive (SPMS; MSSC, 2015). Only about 10% of patients are diagnosed with the third type of MS, primary-progressive (PPMS), whereby symptoms progress slowly over time with no discernible relapse or remission (MSSC, 2015). Based on these findings, it would be reasonable to expect that lower disability scores, reflecting a less progressive type of MS, would be associated with higher resilience.

Riazi, Thompson, and Hobart (2004) also conducted a study on self-efficacy among rehabilitation patients with clinically definite MS (i.e., RRMS) frequently admitted to the hospital for rehabilitation and intravenous steroid treatment. They found self-efficacy to be associated with improved physical and psychological impact of MS scores, lending support to the idea that resilience, being related to self-efficacy, has an effect on individuals' ratings of



physical and psychological impact of MS. While these findings add valuable data to our understanding of the impact of MS in more progressive form of MS, the effect of self-efficacy on participants' physical and psychological impact scores for those with less progressive forms of the disease was not investigated. The present study included participants with all types of MS and assessed their perceived physical and psychological impact of MS with same scale used by Riazi et al. (2004) as a measure of HRQOL (the Multiple Sclerosis Impact Scale-29 (MSIS-29); Hobart, Lamping, Fitzpatrick, Riazi, & Thompson, 2001).

**Participation.** McCabe and O'Connor (2012) examined the coping strategies used by individuals living with various chronic neurological conditions including MS, to help them adjust to the demands of their illness. They found that individuals who demonstrated high adjustment employed specific coping strategies centered around enjoying life and reducing the focus on their condition such as relaxing, listening to music, and decreasing everyday life stresses. Not surprisingly, participants in this group indicated a positive attitude as a helpful coping strategy while participants in the low adjustment group did not. Additionally, well-adjusted individuals participated in recreational activities like sports and other exercise, clubs, and groups more often than those who were less well-adjusted. They also engaged in household tasks more frequently than participants in the low adjustment group. These coping strategies fall into the same three categories (i.e., leisure activities, outdoor activities, and domestic activities) contained on the Frenchay Activities Index (Wade, Legh-Smith, & Langton Hewer, 1985), one of the dependant variables explored in the present study.

Taking a closer look at McCabe and O'Connor's (2012) study, which included participants with Parkinson's disease, Huntington's disease, and motor neurone disease in addition to MS, the number of participants included in the 51-70 and 70 and over age categories

was reported but it was unclear how many of these individuals had MS. The number of years since diagnosis was also reported for participants overall, but there is no indication of what type of MS these individuals had or were diagnosed with. Thus, whether resilience plays a role in the adjustment process or types of coping strategies used by people with various degrees of MS-related disability has yet to be determined. The present study addressed this issue by examining resilience among aging individuals with various types of MS and a wide range of disability levels.

**Healthy lifestyle habits.** Perna et al.'s (2012) study on resilience and health behaviours among elderly people revealed that highly resilient participants 65-years of age and older consumed more fruits and vegetables and engaged in high/moderate physical activity more frequently than non-resilient participants. Likewise, Resnick and Inguito's (2011) study, which aimed to validate the psychometric properties of the RS-25 in a sample of older adults between 80 to 90 years of age, found a positive relationship between resilience and exercise behaviour, and self-efficacy. Min et al.'s (2013) investigation into the resilience levels of outpatients diagnosed with anxiety and depression showed less frequent exercise to be associated with participants in the medium resilience group as opposed to in the high resilience group. Suh, Molt, and Mohr (2010) investigated the association between physical activity and anxiety and depression in a group of individuals in the early stages of MS (mean duration of MS was 3.0 years) and found physical activity to be significantly associated with depression, but not anxiety. This relationship was mediated by participants' level of disability. How resilience is linked to physical activity among people with higher levels of disability/more progressive types of MS however, is not known.

Based on these findings and those discussed in the participation section above, highly resilient individuals would be expected to frequently participate in leisure, outdoor, and domestic activities, exercise regularly, and practice healthy eating habits. Since previous research examined mainly older populations without a chronic illness, whether resilience impacts health and lifestyle habits as one ages with MS is not clear.

**Social support.** Another important lifestyle factor related to resilience is social support. Among the recreational and relaxation coping strategies adopted by participants with MS and other neurological conditions in McCabe and O'Connor's (2012) study, "social supports were endorsed as being the most helpful in coping with the illness" (p. 22). A greater number of participants who scored high on adjustment described their friends and family as the social support they relied on while those who scored low on adjustment were more likely to endorse clubs/activity groups and support groups as sources of social support (McCabe & O'Connor, 2012). Individuals who demonstrated higher levels of adjustment called upon supports to help them maintain their level of functioning despite their illness while participants who demonstrated lower levels of adjustment were more likely to ask their supports to complete tasks for them.

Participants in McCabe and O'Connor's (2012) study were also asked which components of QOL were most important to them. Respondents in the high adjustment and low adjustment groups agreed that social support was most important, however, participants' responses in the highly-adjustment group were higher. Moreover, social support was identified as a major protective factor that helped individuals with chronic disabilities at major turning points in their lives in King et al.'s (2003) study discussed earlier.

Pietrzak and Cook (2013) examined the psychological resilience among older United States veterans including measures of potentially traumatic events over their lifetime, current Post Traumatic Stress Disorder, major depression, and generalized anxiety symptoms. Participants were divided into three groups: control (low number of lifetime traumas, low current psychological distress), resilient (high number of lifetime traumas, low current psychological distress), and distressed (high number of lifetime traumas, high current psychological distress). Close to 70% of veterans who had experienced a high number of traumas were in the resilient group. Compared to members of the distressed group, veterans in the resilient group obtained higher scores on measures of social connectedness, which includes social support and protective psychosocial characteristics such as community integration. Overall, higher levels of resilience appear to be related to greater social support.

McCabe and O'Connor's (2012) study has been the only investigation into the relationship between resilience and social support in MS. As mentioned earlier, their study included participants with a variety of neurological illnesses other than MS. This was also a qualitative study and included only a small number of patients with MS ( $n = 11$ ). Their exact ages were also unknown. Building on McCabe and O'Connor's (2012) findings, the current study investigated social support in over 700 individuals over the age of 55 with MS to further examine the role of social support as it relates to resilience in this population.

**Mental health, alcohol use, and smoking.** Generally speaking, it would be reasonable to suggest that low levels of resilience could be related to negative health and lifestyle behaviours although this phenomenon has not been examined in patients living with MS. In other groups, such as survivors of childhood trauma, this relationship has been proposed. Wingo, Wrenn, Pelletier, Gutman, Bradley and Ressler (2010), for example, examined the effects of resilience

on depression among individuals who experienced child abuse or had been exposed to trauma. They found that resilience not only predicted depression severity but also interacted with trauma exposure to moderate this relationship. Referring back to Hardy, Concato, and Thomas' (2004) findings on resilience and symptoms of depression described at the beginning of this section, Goldstein, Faulkner, and Wekerle (2013) examined several external negative outcomes (external measures of resilience) and behavioural outcomes related to participants' level of resilience (internal resilience) among a sample of adults transitioning out of the child welfare system who had been exposed to some form of maltreatment. Symptoms of depression were found to be negatively related to internal resilience. Internal resilience also added to the prediction of depression above and beyond the influence of various child abuse and neglect factors and was found to significantly interact with sexual abuse wherein "high resilience was associated with a reduction in depression scores at higher levels of sexual abuse" (Goldstein, Faulkner, & Wekerle, 2013, p.1). Furthermore, internal resilience was negatively associated with smoking of cigarettes and nicotine dependence in the previous year.

Adding to Wingo et al.'s (2010) and Goldstein et al.'s (2013) findings, Wingo, Ressler, and Bradley (2014) conducted a study on inner-city adults with a history of childhood abuse to examine the influence of resilience characteristics on substance use. Because resilience refers to the ability to adapt or cope with adversity or trauma, Wingo and colleagues (2014) hypothesized that greater resilience would be associated with fewer alcohol and drug use problems. Their results strongly supported this prediction as resilience characteristics mitigated both alcohol use problems and drug use directly and in combination with the severity of childhood abuse.

Turning now to the variety of traumatic experiences including chronic illness that occur in the medical field, patients may possess a variety of protective factors such as resilience to

combat psychological distress. Mautner et al., (2013), for example, examined the influence of resilience on psychological outcomes in women who experienced preeclampsia, a serious pregnancy complication that can place the mother and fetus' health at risk. Their results revealed that women with high levels of resilience experienced significantly less depression as well as better mental health than women with low resilience. Mental health scores combined with scores of physical health operated as a measure of participant's HRQOL similar to one of the HRQOL measures in the current study.

Looking at resilience from more of a clinical perspective, Min et al. (2013) mentioned earlier in the 'healthy lifestyle habits' section, examined the characteristics associated with low resilience in outpatients diagnosed with depression and/anxiety disorders and found trait anxiety to be a contributing factor in low and medium resilience as opposed to high resilience groups. In describing their perception of resilience in the process of learning to adapt to life with chronic illness, one participant in Kralik et al.'s (2006) study talked about resilience as it relates to depression. They wrote, "We feel really bad and often feel down with it and then we gradually bounce back again, until it all happens again" (p. 194). This statement may demonstrate one's experience of resilience despite periodic symptoms of depression.

Similar associations between resilience and symptoms of anxiety and depression have been found in youth (age 13-15; Skrove, Romundstad, & Indredavik, 2013) and college students (Campbell-Sills, Cohan, & Stein, 2006). Campbell-Sills, Cohan, and Stein (2006) found resilience to be a moderating variable in the relationship between emotional neglect, and anxiety and depression while Skrove, Romundstad, and Indredavik (2013) observed resilience characteristics to be related to lower levels of substance use.

Stress is another psychological variable that has been linked to higher levels of resilience in different populations including the medical field as discussed earlier. Abdollahi, Talib, Yaacob, and Ismail (2014) investigated perceived stress among nurses whose job is known to be stressful. They considered how hardiness, which is related to resilience, served to protect participants against stress and found that greater hardiness was linked to lower levels of perceived stress among the nurses. March (2004) also found perceived stress to be negatively associated with resilience when investigating life adversity and resilience in late life. Therefore, lower levels of stress appear to be positively related to resilience.

The relationship between stress and MS is multifaceted as it incorporates psychological, social, and biological factors associated with subsequent exacerbations (i.e., 'attacks') and disability progression (Artemiadis, Anagnostouli, & Alexopoulos, 2011; Mohr, 2007; Mohr, Hart, Julian, Cox, & Pelletier, 2004). Psychological and social factors, including depression, and poor coping and social skills discussed earlier, have been shown to enhance the relationship between stress and MS symptoms (Mohr, 2007) and negatively affect QOL (Senders, Bourdette, Hanes, Yadav, & Shinto, 2014). While the scope of this study does not include the effects of stressful life events on neurological symptoms such as the development of lesions in the brain (see Senders et al., 2014), because several of the body's systems, including the autonomic nervous system and hypothalamic-pituitary-adrenal axis, "are closely tied to both the innate and adaptive immune responses... it seems logical that stress could affect the immune system and an immune-mediated disease like MS" (Lovera & Reza, 2013, p. 398). It is plausible that individuals with MS who are highly resilient would experience less stress because they are better able to respond or adapt to psychological, biological, or social factors that could result in a stress response. How

stress affects older individuals with MS with varying levels of resilience, however, has not been previously addressed in the literature

**Gender, education, age, and income.** When it comes to describing resilience demographically, a number of variables including sex or gender, education level, age, and income have been studied among members of the general population with a shortage of research among people with MS based on this author's search of the literature for this thesis. Earlier it was noted that men generally exhibit greater resilience than women in response to stressful life events (Hardy, Concato, & Thomas, 2004). The same effect was found by Campbell-Sills, Forde, and Stein (2009), in a study that examined predictors of resilience in a community sample. In fact, being a female and having a lower level of education and income were associated with lower resilience. Conversely, Fraser and Polito (2007) found that women living with MS scored higher than men living with MS on two different elements of self-efficacy (i.e., belief in their ability to function and ability to control their MS), although only the former result was significantly different.

With regard to education, Mandemakers and Monden (2010) found that education buffered the impact of disability on psychological distress (i.e., anxiety, depression) in a sample of young to middle-age adults (i.e., 23-33). This period of time is critical as these young people are building their careers (Ploughman et al., 2015). This is also the age that MS is typically diagnosed (MSSC, 2015). Pietrzak and Cook (2013) also found that Veterans in the resilient group, as opposed to the control or distressed groups, were more likely to have college level education or higher.



diagnosed (MSSC, 2015). Pietrzak and Cook (2013) also found that Veterans in the resilient group, as opposed to the control or distressed groups, were more likely to have college level education or higher.

When considering age, Wagnild (Resilience Center, n.d.a) refers to a study of 1061 middle-age adults who completed the online RS that strongly suggests that scores on the RS increase with age. The average RS score for individuals over the age of 60 was 143 while the average score for individuals who were 30 or younger was 133. Looking at the discrepancy in the scores over time, Wagnild concluded that RS scores increased 2-3 points for every 10 years (Resilience Center, n.d.a). Lundman and colleagues' (2007) investigation of the relation between resilience and age in eight different samples involved in testing the Swedish version of the RS also uncovered a positive association between the two variables. Their results indicated that RS Scores increased by 0.134 points each year, which is less than the rate cited by Wagnild (Resilience Center, n.d.a). This may be due to the fact that participants' levels of resilience in Lundman et al.'s (2007) study were high, therefore, minimizing increases' in resilience due to age over time.

Conversely, in conducting their study on a sample of older women, Wagnild and Torma's (2013) findings revealed that moderate-to-high levels of resilience were not significantly associated with age, education or income but were related to a health-promoting lifestyle that included measures of exercise, nutrition, interpersonal support, and stress management. They also found that moderate-to-high levels of resilience were related to participant's self-reported health status discussed more fully in the previous section. In her 2003 study on resilience and successful aging, Wagnild reported conflicting relationships between resilience and level of income, where higher income respondents reported higher resilience scores in one of two

samples of elderly participants examined in the study. Based on these results, Wagnild (2003) acknowledged that it is not possible to definitively state whether there is a relationship between resilience and level of income. Providing some clarity to this issue, McCabe and De Judicibus (2005) determined that economic pressure as well as MS-related costs predicted QOL in participants with MS. Economic pressure was also found to be associated with participants' psychological well-being (i.e., depression, anxiety, fatigue, and confusion).

**Relationship between resilience, disability, participation, and QOL in MS.** Because of its progressive nature, it is plausible to expect that greater levels of disability apparent in more advanced stages of MS would result in reduced levels of QOL and vice versa. The relation between attitudinal beliefs and disease state was examined by Evers and Karnilowicz (1996) in a sample of patients with MS. They compared individuals who identified their MS as being either 'chronic progressive' (i.e., SPMS or PPMS) or 'in remission' (i.e., RRMS). Participants with more progressive states of MS reported significantly greater frustration with daily activities, including personal mobility, activity level, and ability to work. They also had more difficulty coping with symptoms of MS and feelings of loneliness and isolation (Evers & Karnilowicz, 1996). As a result, individuals in earlier stages of the disease had a more positive attitude towards their condition than those with a more progressive type of MS.

Like Evers and Karnilowicz (1996), Wassem (1991) tested the relationship between health locus of control and course of MS in a group of individuals age 21 to 78 (mean age of 47) who had MS for an average of 16 years. Wassem (1991) discovered that participants who were more internally oriented (internal locus of control discussed earlier) were more knowledgeable about MS, practiced more self-care activities to maintain health and well-being, and had a milder course of MS, than participants who were externally oriented (external locus of control).

Presumably, individuals who believed they can affect outcomes in their lives experienced less disability/were in the earlier stages of MS. Fraser and Polito's (2007) results support these findings as they found significant differences in self-efficacy between participants with RRMS and more progressive forms of MS. Both men and women with RRMS had a greater belief in their ability to function and control their disease compared to those with more progressive forms (Fraser & Polito, 2007).

Looking at individuals' level of disability instead of their disease state, Krokavcova et al. (2008) explored mastery defined earlier as a product of resilience and its association with functional disability and perceived health status, and well-being among patients with MS. Functional disability refers to an individuals' ability to participate in employment, educational, leisure, and social activities (Krokavcova et al., 2008). Separate measures of physical and mental health status were examined in two groups: younger participants (less than 45 years of age) and older participants (45 years of age or older). Functional disability was found to be significantly negatively related to perceived physical health status in both age groups while it significantly predicted perceived mental health status in only the group of younger patients. Mastery, on the other hand, was significantly positively associated with perceived mental health status in the group of older patients. These findings not only suggest a relationship between level of functional disability and perceived physical health status regardless of one's age but also an effect of mastery on perceived psychological health status among older individuals. Mastery appears to have an important role in how older people with MS view their overall health, reflected in QOL.

The present study will add to Krokavcova et al.'s (2008) findings in several ways. First, investigations into resilience described earlier as a precursor of mastery and perceived health,

and well-being, are carried out in a greater number of participants adding to the validity of the findings. Secondly, the findings of the current study also reflect outcomes pertaining to health and well-being of Canadians with MS, which may be different from those found in other parts of the world like Slovakia, which is where Krokavcova et al.'s (2008) study was conducted. Thirdly, the results presented in the current study represent older individuals 55 years of age and older with MS as opposed to middle-aged participants with MS whose average age was 38.3 (+/- 10.6) and older participants with MS whose average age was 50.8 years old (+/- 4.9) in Krokavcova et al.'s (2008) study.

**The role of resilience in aging.** Based on the evidence presented thus far, if resilience modifies outlook, participation, and health behaviors then one could assume that resilience is also a catalyst for 'healthy aging'. Thus, adding to Krokavcova et al.'s (2008) findings, Smith, Young, and Lee (2004) investigated whether positive psychological characteristics, namely optimism and health-related hardiness, were associated with health and well-being in older women. Participant's physical health along with a number of other variables were taken into account in the analysis, therefore, the results may be applied to older individuals without a chronic disease or disability. These findings have the potential to add a unique perspective of resilience among persons aging with chronic illnesses like MS. Health-related hardiness and optimism explained a significant proportion of the variance in perceived stress and HRQOL, which captured participants' physical and mental health (Smith et al., 2004). Quality of life and well-being are strongly related to positive attributes that reflect older individuals' positive expectations and ability to confront challenges.

Several researchers reviewed earlier consider resilience and related psychological characteristics to be individual attributes that promote positive adaptation to adversity by

moderating the negative effects of stress. In a study on community-dwelling older persons, Kempen et al. (1999) investigated individuals' functional limitation, level of disability, and various psychological attributes, including mastery and self-efficacy expectancies. Specifically, they examined the moderating effect of these psychological variables on the association between function limitations and disability, which was assessed according to participants' IADL/ADLs. Although support for a moderating effect was not found, Kempen et al. (1999) did find that lower levels of mastery and self-efficacy expectancies were associated with higher levels of IALD/ADLs, irrespective of level of functional limitation (e.g., motor limitations, short-term memory, vision or hearing loss, global cognitive function). This suggests that the presence of resilience in older adults is related to their ability to perform domestic and personal care activities and level of disability.

**Resilience and healthy aging with MS.** With an aging population and the number of people with MS over the age of 55 increasing (Marrie, Yu, Blanchard, Leung & Elliott, 2010), the interest in factors associated with healthy or successful aging is growing. One factor in particular is resilience, found to be a foundational factor of healthy aging in Ploughman et al.'s (2012a) study below. Because resilience is commonly thought of as an enduring personality trait (Wagnild & Young, 1993), it seems plausible that, "it persists into old age even when physical health declines" (Wagnild, 2003, p. 43).

Evers and Karnilowicz' (1996) findings discussed earlier were reflected in Ploughman et al.'s (2012a) qualitative study on factors influencing healthy aging with MS, in which participants 55 years of age and older had had MS for 20 years or more, indicated critical proximal factors they considered invaluable to their QOL. These included effective and accessible healthcare, healthy lifestyle habits, maintaining independence at home, and work and

social engagement. Four foundational factors were found to support these critical factors: mental/cognitive health, social support, financial flexibility, and resilience. Resilience was composed of "subthemes relating to the participants' ability to adapt to change and disease symptoms, seek out and gain new knowledge, . . . deal with uncertainty, resolve problems on one's own, and cope with and overcome barriers" (Ploughman et al., 2012a, p. 29). Participants who provided these responses were more likely to reach the critical proximal factors related to healthy aging in MS. Individuals who described resilience were also more likely to have a positive outlook compared to those who responded with more negative statements.

Similar to Ploughman et al.'s (2012a) findings related to subthemes of resilience, Haynes and Watt (2008) discovered focus/adaptation to play a crucial role in the healthy behaviours of resilient individuals living with debilitating illnesses such as MS. Participants' accounts of their experience with MS in this study also illustrated several components of resilience, including equanimity and perseverance. These components are evident in such statements as, "Well I've learned to live with it... You have to go on and do it and know it's there" (Hayes & Watt, 2008, p. 47) and "You know you got it, you learn over a period of time that you're going to have to live with [it] so... you just go on" (Hayes & Watt, 2008, p. 47). These statements lend further support to the key role of resilience in health and well-being in the aging process.

Successful aging, defined as, "the health and vigour of the mind, body, and spirit into middle age and beyond" (Wagnild, 2003, p. 43), is a concept related to healthy aging. Many argue that it also entails freedom from impairment and the ability to live independently (Wagnild, 2003). This, however, may not always be the case as Montross et al. (2006) found that most participants in their study thought of themselves as aging well despite having a chronic illness or disability (Wagnild & Collins, 2009). These findings reflect the World Health

Organization Constitutional statement that, "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 2015).

Related to successful aging, Dalmonte, Finlayson, and Helfrich (2004) investigated the coping processes of 23 women aged 55 years and older who were diagnosed with MS for at least 15 years. Data gathered through in-depth qualitative interviews suggested that being able to adapt to change and having confidence in one's own ability to cope with stress in addition to a positive outlook on life were critical to individuals' psychological well-being. Having an optimistic attitude allowed participants to focus on positive aspects of their lives and deterred them from focusing on the negative elements (Dalmonte et al., 2004). Black and Dorstyn's (2013) study, which tested a biopsychosocial model of resilience for MS, also lends support to Dalmonte et al.'s (2004) findings as they found positive affect and self-efficacy to be the strongest predictors of resilience in their study. Therefore, an individuals' positive outlook along with their personal resources contribute to resiliency and aspects of QOL.

Dalmonte et al.'s (2004) qualitative study does however, have some limitations which the current study aims to improve upon. While Dalmonte et al. (2004) were able to gather in-depth data related to coping with stress and having a positive approach to life from 23 older individuals with MS, the present study collected information from over 700 older adults across Canada. Dalmonte et al.'s (2004) findings are also limited to the perspectives of older women, leaving the coping mechanisms and attitude of men in this age bracket unknown. The current study included 166 men (22.3% of the sample) 55 years of age and older with MS who provided information related to disability, daily participation, and HRQOL to fully inform our understanding of resilience.

## **Study Rationale**

Based on the research presented above, there are several gaps in the research related to resilience and healthy aging with MS. The research cited on diet and physical activity, for example, was based on older individuals ages 65 through 90 without chronic disease. Seeing as MS is a neurological disease that affects motor function, data on physical activity among individuals in this population would be beneficial. Other areas where studies on MS were lacking were in the mental health field (i.e., anxiety, depression, and stress) and lifestyle behaviours, such as smoking and alcohol use. Studies on mental health related to persons with MS or any chronic illness are particularly important as positive factors such as resilience have the potential to profoundly impact level of disability and various health-related outcomes including HRQOL. New research on health and lifestyle behaviours suggests that smoking, for example, can accelerate disease progression (D'Hooghe, Haentjens, Nagels, & De Keyser, 2012). The literature related to demographic information such as age, gender, education, and income was also based on resilience in healthy aging individuals or general members of the population (i.e., without neurological illness). Dalmonte et al.'s (2004) study did focus on aging participants with MS, however their findings related to coping and outlook on life were only based on women aging with MS. Thus, this study aims enhance the existing research by providing current information on resilience as it relates to these and other study variables in an aging population of individuals 55 years of age and older with MS.

This study's overall aims and objectives were to: (1) determine if there are any differences in demographics, health, lifestyle, and participation in daily activities among older people with MS who report high and low levels of resilience and (2) understand how resilience affects the relationship between disability and HRQOL, and participation. Based on the research



discussed in this chapter, it was expected that participants in the high resilience group would differ from those in the low resilience group with regard to age (older), gender (male), smoking status (non-smoker), and level of disability (more independent). It was hypothesized that participants in the high resilience group would exercise and participate in domestic, outdoor, and leisure activities more often, consume a healthier diet and less alcohol, and perceive their health more positively than participants in the low resilience group. Highly resilient individuals were also expected to have achieved a higher level of education and financial security, have better perceived health, and experience less stress, anxiety, depression, and physical and psychological impact of MS than less resilient participants. Furthermore, it was hypothesized that resilience would moderate the relationship between level of disability and both HRQOL and daily participation. Perseverance was also expected to capture a large proportion of the variance in participation and HRQOL due to its semblance with having a survivor attitude. The methods of this study will be discussed in Chapters 2 and the results of these proposed relationships will be discussed in Chapter 3 followed by a discussion in Chapter 4.

## Chapter Two

### Methods

**Participants and sampling.** Participants in this study were recruited by Ploughman and colleagues (2014) and comprised the data for *The Canadian Survey of Health, Lifestyle and Aging with Multiple Sclerosis*. The survey's aim was to examine health and lifestyle factors that may contribute to healthy aging among older people with MS. Participants were Canadians 55 years of age and older and were recruited between May 2011 and December 2012 through the use of public advertising on the Multiple Sclerosis Society of Canada Research Internet Portal (MS Society of Canada, 2012), telephone lists of eligible MS clinic patients, newspaper advertisements, and local MS Society chapters. The study was approved by eleven health research ethics boards in eight Canadian provinces prior to recruitment. All participants had self-reported MS symptoms for 20 years or more, had a confirmed diagnosis from a neurologist, or provided a neurologist's name and diagnosis date in order to confirm their diagnosis. Ploughman et al. (2014) used an exhaustive sampling technique to obtain a large representative sample, repeatedly advertising in regional newspapers, making contacts with MS Society Chapter support groups, and following-up at study sites.

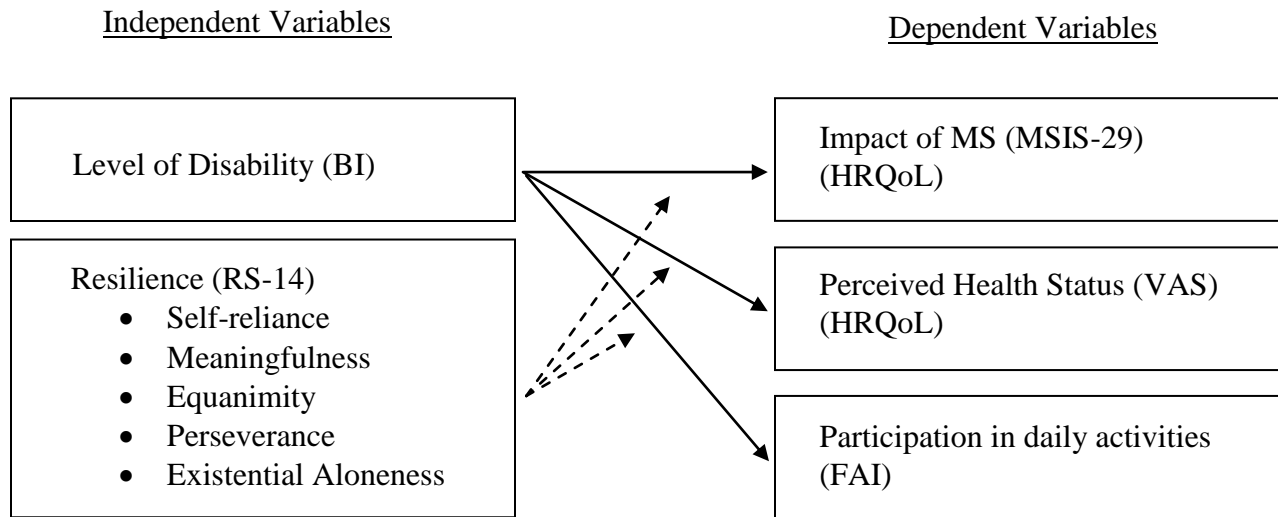
Participants' informed consent was obtained using a standard script over the telephone. Questionnaires available in both English and French were mailed to participants with an information sheet, prepaid return envelope, toll-free telephone helpline number, and email address. Participants were asked to complete and return the survey over a two-week period. A follow-up call was made to those who did not respond after four weeks (Ploughman et al., 2014). Completing the survey by telephone was also an option. A total of 743 surveys were completed, each of which was coded to maintain anonymity.

**Survey design.** The survey consisted of validated self-reported outcome tools in addition to custom-designed questions selected based on a pilot study with a small number of individuals with MS (Ploughman, Austin, Stefanelli, & Godwin, 2010). The survey was divided into sections that grouped similar-type questions together. Participants were asked to complete sections in the order they were presented and to take breaks in between sections (Ploughman et al., 2014). Within each section, questions related to involvement in activities that followed similar timelines (e.g. weekly, monthly, or yearly) were placed in sequence with one another as difficulties with temporal-based questions were noted (Ploughman et al., 2014). The first 11 respondents to return the finalized version of the survey were asked to provide comments on its form and function that was incorporated into the final version. These responses, however, were omitted from the final dataset (Ploughman et al., 2014). The final survey was comprised of five sections: You and your MS, Your health, Your activities, Your thoughts and feelings, and Your social life. These were followed by open response questions for participants to make any additional remarks. All variables examined were entered into a dataset prior to this investigation. Variables and their subcomponents were summed and coded accordingly. The proportion of missing data was low (5.4%) and was dealt with using three different imputation techniques: deductive imputation, person mean substitution and 'hot deck' imputation (see Ploughman et al., 2014 for details).

**Study variables.** Based on previous research, a number of 'a priori' variables in the dataset associated with resilience in MS and other chronic conditions were considered in the current analysis (see Figure 2). To determine the contribution of resilience to living and aging with MS, two independent variables were investigated: resilience and level of disability. Two dependent variables were also examined: HRQOL, comprised of two separate measures looking at the impact of MS on functioning and perceived HRQOL, and participation. As stated earlier, it

was hypothesized that these variables in addition to a number of other 'a priori' variables would be different in participants with high and low resilience. Details of these measures are provided below.

Figure 2. Model of study variables.



The first independent variable in this study was resilience, measured using the Resilience Scale (RS-14; Resilience Center, n.d.b). The RS-14 is a reduced version of the 25-item Resilience Scale (RS) created by Wagnild and Young (1993), which has been validated in older community-living individuals. The RS-14 is derived from the original resilience scale items that had the highest inter-item correlations (Aiena, Baczwaski, Schulenberg, & Bauchanan, 2015). These items reflect the five characteristics of resilience described by Wagnild and Young (1990, 1993) that include perseverance (Items 6 & 8), equanimity (Items 3 & 10), meaningfulness (Items 2, 9, & 13), self-reliance (Items 1, 5, 7, 12, & 14), and existential aloneness (Items 4 & 11). Item responses, which range from 1 (disagree) to 7 (agree), were summed for a total score ranging between 14 and 28. These scores can be further classified as very low resilience (i.e., scores ranging between 14 - 56), low resilience (i.e., 57 - 64), moderately low resilience (i.e., 65 - 73), moderately high resilience (i.e., 74 - 81), high resilience (i.e., 82 - 90) and very high

resilience (i.e., 91 - 98) (Aiena, Baczwaski, Schulenberg, & Bauchanan, 2015). Participants who scored in the 'high' and 'very high' categories were considered to be high in resilience for the purpose of this study. Respondents with scores lower than 82 were considered to be low in resilience. Descriptors of general item content can be found in Wagnild (2009).

The second independent variable in this study was level of disability, measured using the Barthel Index (BI). The BI measures a person's function and mobility in 10 different ADLs: feeding, bathing, grooming, dressing, toileting, bladder control, bowel control, ambulation, transfers, and stair climbing (Mahoney & Barthel, 1965). Item ratings correspond to whether an individual engages in activities independently, with some assistance, or are completely dependent. A total score of 100 indicates complete independence while a score of 0 indicates that complete assistance is required. Item scores can also be categorized into different levels of dependence. A score of 100 suggests that an individual is independently ambulatory, can ascend and descend stairs on his/her own, and is able to perform daily activities without help. Scores of 91-99 suggest slight dependence, 61-90 moderate dependence, 21-60 severe dependence, and 0-20 complete dependence (Katz, 2003). Thus, higher scores indicate lower levels of disability/dependence. The BI has been shown to be reliable whether administered by telephone, by mail, or in person (Yeo, Faleiro, & Lincoln, 1995), and has been tested among persons with MS (Cano, O'Connor, Thompson, & Hobart, 2006; Nicholl, Hobart, Dunwoody, Cramp, & Lowe-Strong, 2004; van der Putten, Hobart, Freeman, & Thompson, 1999).

To examine the effects of disability and resilience on participant's HRQOL and participation, two dependent variables were investigated. The first was HRQOL, measured using two instruments: the MSIS-29 and a perceived rating of health status. The MSIS-29 consists of 29 questions and is scored according to a 5-point Likert scale (Hobart et al., 2001). Twenty

questions addressed the physical impact of MS (range of 20-100), and nine addressed the physiological impact of MS (range of 5-45), generating a combined score as a percentage of 100. Higher scores indicate a greater impact of MS. Participants also rated their HRQOL along a visual analogue scale (VAS) adapted from the EQ-5D health outcomes questionnaire (Groenvold, Klee, Sprangers, & Aaronson, 1997). Respondents marked a line to indicate their perceived health state that was later measured as a point from 0 to 100 in millimeters and converted to a percentage score of 0 to 100. In addition to being pre-tested within an older population of individuals with MS (Ploughman et al., 2010), the full EQ-5D was found to demonstrate good test-retest reliability and construct validity in a clinical registry population of people with this disease (Fisk et al., 2005).

The second dependent variable was participation in IADL/ADLs measured using the Frenchay Activities Index (FAI). The FAI assesses the frequency of participation in household (domestic), leisure, and outdoor activities with summed scores ranging from 5 to 20 (Wade, Legh-Smith, & Langton Hewer, 1985). Added together, these scores make up the total FAI score, ranging from 15 to 60. Higher scores indicated more frequent participation in the activity. The FAI highly correlates with interview scores (Carter, Mant, Mant, Wade, & Winner, 1997) and has excellent test-retest reliability when used as a mail-out survey (Turnbull et al., 2000). It has also been used in large MS population studies (Einarsson, Gottberg, Fredrikson, von Koch, & Holmgvist, 2006; Ytterberg, Johansson, Gottberg, Holmgvist, & von Koch, 2008).

The second part of the study aimed to determine the differences in health and lifestyle behaviours among participants with high and low resilience. The Simple Lifestyle Indicator Questionnaire (SLIQ) variables of interest include diet, exercise, smoking, alcohol consumption, and lifestyle stress. This instrument has been pretested on older people with MS (Ploughman,

Austin, Stefanelli, & Godwin, 2010). Initial content and face validity of the SLIQ were measured by the developers of the instrument (Godwin et al., 2010). Diet scores were calculated based on participants' responses to three items indicating how often they consumed particular healthy foods (range of 0-5), with total scores ranging from 0 to 15. Similarly, exercise participation was determined by adding the number of times participants engaged in light exercise (e.g., light housework, leisurely walking), moderate exercise (e.g., brisk walking, swimming, dancing), and vigorous exercise (e.g., running, heavy yard work, cross-country skiing) for 30 minutes or more each week, with scores ranging from 0 to 54. With regard to smoking, participants received a score of 0 if they were a smoker at the time of testing, 1 if they previously smoked, and 2 if they never smoked. Higher scores on each of these components indicate a healthier lifestyle (Godwin et al., 2008). Raw scores of alcohol consumption was tabulated by adding up the number of alcoholic drinks (i.e., 3-5 oz of wine, 10-12 oz or 1 bottle of beer, 1-1½ oz of any spirit) consumed in an average week. Finally, participants indicated their level of daily stress on a scale of 1 to 6, with 1 being very stressful and 6 being not at all stressful.

Participants' mental health was measured using the Hospital Anxiety and Depression Scale (HADS), a self-assessment screening tool found to reliably screen for anxiety and depression in patients with MS (Honarmand & Feinstein, 2009). It consists of two subscales: the Anxiety subscale and Depression subscale. Each subscale contains seven intermingled items scored on a four-point Likert scale (0-3). Total scores range of 0 to 21. Lower scores indicate fewer symptoms (scores of 0 not included in possible range; Zigmond & Snaith, 1983). The Personal Resources Questionnaire (PRQ-2000) was also used to measure social support (Weinert, 1987). This scale consists of 15 items, to which participants agreed or disagreed according to a seven-point Likert scale (1-7), with higher scores indicating higher support. The

PRQ-2000 has demonstrated good internal consistency, and good predictive and construct validity in multiple chronic disease data sets (Weinert, 1987). Mail versions of the scale have also been used in adults with MS (Long & Weinert, 1992) and community-dwelling women with chronic health conditions (Weinert, Cudney, & Hill, 2008)

Lastly, to assess financial stability, participants were asked which statement best describes their financial situation: 'I have more than enough money to meet my needs so I can live the way I want', 'I have enough money to meet my needs so I can live the way I want', or 'I do not have enough money to meet my needs so I can live the way I want'. They were also asked what was the highest grade of high-school or post-secondary education they had completed to measure their level of education.

Cronbach's alpha was computed for each of the study variables. Cronbach's alpha is the most commonly cited measure of reliability in the literature. Alpha values range from 0 to 1, with higher values indicating greater internal consistency. Nunnally (1987) recommends using scales that have an alpha level of 0.7 or higher to ensure reliability. Cronbach's alpha values between .60 to .70 are considered to be at the lower limits of acceptability (Hair, Black, Babin, & Anderson, 2010). Alpha was 0.96 for the physical items and 0.91 for the psychological items of the MSIS-29 and 0.96 for the physical and psychological components combined. For the FAI, Cronbach's alpha was 0.88 for household participation, 0.61 for leisure participation, 0.71 for outdoor participation, and 0.88 for total participation. Alpha levels for diet and exercise items were 0.61 and 0.60, respectively, however the alpha value of 0.59 was on the cusp of the acceptable range for anxiety and depression. Cronbach's alpha was high for the 14 items of the RS at 0.92 and in the high to moderately high range for each of the characteristics of resilience: perseverance ( $\alpha = 0.75$ ), equanimity ( $\alpha = 0.65$ ), meaningfulness ( $\alpha = .75$ ), self-reliance ( $\alpha = .81$ ),



and existential aloneness ( $\alpha = .79$ ). Reliabilities were not generated for the visual analogue scale, alcohol consumption, life stress or smoking because these were measured according to one item. Due to the way in which items on the BI were scored as a result of additional responses options being generated to measure participants' functional mobility, Cronbach's alpha could not be calculated for this variable.

**Data analysis.** Analysis of Variance (ANOVA) tests were conducted to explore the differences between 'a priori' variables amongst participant groups with high and low resilience. Resilience Scale cut-offs determined by the scale's developer (Wagnild, 2009) were followed when dividing participants into high and low resilience groups as described earlier. Significance and *F*-values were calculated at the 95% confidence level.

Multiple regression analyses were conducted to examine the effect of participants' disability and resilience on their HRQOL and daily participation using the Statistical Package for the Social Sciences (v20). Frequencies and descriptive statistics (e.g., means, standard deviations, etc.) were also calculated to determine participant characteristics. Distributions of these variables, including each of their subcomponents, were checked for normality before further analysis (Huck, 2012). Any outliers on a given variable remained in the data set as there were few and would be insignificant due to the large sample size. Hierarchical regression analyses were carried out to examine the effect of resilience on each of the dependent variables (i.e., MSIS-29, VAS, FAI) when controlling for disability (measured using the BI). Resilience was added on the second step of these analyses to determine the proportion of added variance.

Since resilience is comprised on subcomponents, the contribution of each of the five characteristics of resilience on each of the dependent variables was examined. It was

hypothesized that perseverance would have a significant effect on participants' HRQOL and participation above any of the other characteristics, supporting the presence of a survivor attitude. The strength of association between the independent and dependent variables in each model was determined using *R* values, including  $R^2$  and  $R^2$  change, at the 0.05 significance level. Casewise diagnostics were examined to measure the fit of each model in which resilience or one of the five components of resilience was added. This procedure identified the number of cases in the dataset with standardized residuals that exceeded three standard deviations and therefore, were not accounted for by the model.

## Chapter Three

### Results

**Participant demographics.** Participants ( $n = 743$ ) ranged from 55 to 88 years of age with a mean age of 64.6 years ( $SD = 6.18$ ). Five hundred and seventy-seven (77.7%) women and 166 (22.3%) men described experiencing MS symptoms for 14 to 73 years with a mean duration of 32.85 years ( $SD = 9.52$ ) and reported an average time of 8.04 years ( $SD = 9.39$ ) with a range from 0 to 47 years from onset of symptoms to diagnosis. Participants' resilience scores were high, falling into the moderately high range ( $M = 77.73$ ), including each of the components of resilience (See Table 1). There was great variability in respondents' overall resilience scores ( $SD = 13.35$ ), ranging from 23 to 98; 98 being the highest possible resilience score. This variation was ideal as it allowed for comparisons between participants who were high in resilience with those who were low in resilience. Resilience scores in both groups were normally distributed with skewness and kurtosis scores for low (-1.08 and .118, respectively) and high resilience (1.11 and -1.21, respectively) within the acceptable range as described by Huck (2012). Additionally, participants' average BI score was 76.17 ( $SD = 24.78$ ) on a scale of 0 to 100, where lower scores indicate greater disability. Fifteen percent of participants were categorized as being independent and almost half (47%) were categorized as having a moderate level of disability.

With regard to daily participation, nearly half (50.6%) of the participants frequently engaged in household activities such as preparing meals, washing clothes, or doing housework, compared to 13.4% and 27.9% who frequently engaged in leisure and outdoor activities, respectively. Participants' mean rating of the impact of MS fell in the 'little' to 'moderate' impact range, with a score of 77.96 out of 100 ( $SD = 25.64$ ). They reported that the physical impact of MS was slightly greater ( $M = 56.87$ ,  $SD = 19.95$ ) than the psychological impact ( $M = 21.09$ ,  $SD$

= 8.13) within a range of 20 to 100 and 9 to 45, respectively. Similarly, their perceived health ratings had an average score of 55 on a scale of 0 to 100.

**Characteristics of participants with high and low resilience.** Of the 743 participants, 330 (44.4%) reported high levels of resilience. The average resilience score in this group was 89.28, which was at the top of the 'high resilience' category in the scoring of the RS-14. By comparison, 413 participants (55.6%) reported low levels of resilience. The average score of 68.49 in this group falls within the 'moderately low' range ( $M = 68.49$ ,  $SD = 10.42$ ).

The majority of variables examined in each of the resilience groups were normally distributed with skewness and kurtosis values within the acceptable range of -1.00 to +1.00 as described by Huck (2012). Alcohol consumption was positively skewed (3.84) and highly leptokurtic (25.36) with 51.8% of participants indicating they do not drink alcohol. Physical activity was also slightly positively skewed (1.34) and leptokurtic (2.31) with a higher proportion of participants engaging in light to moderate exercise as opposed to vigorous exercise over the course of the week. The PRQ-2000, which measures social support was close to the acceptable limits of skewness (-1.13) and kurtosis (1.31) as participants generally felt a high degree of social support. Lastly, 65% of participants indicated that Grade 12 was the highest level of education they had completed, resulting in non-normative skewness (-2.16) and kurtosis (5.92) statistics. Just under half of the variables also failed Levene's test of homogeneity of variances, indicating that sample characteristics may be different from others in the MS population. Analysis of Variance test was conducted on these variables without any transformations.

Looking at the study variables, participants with high levels of resilience rated their perceived health higher and the physical and psychological impact of MS significantly lower than individuals in the low resilience group (see Table 1). A significantly greater proportion of

individuals in the high resilience group also reported frequent participation in domestic, leisure, and outdoor activities. Meanwhile, a higher percentage of participants in the low resilience group indicated they participated in leisure activities occasionally or rarely (See Figure 3). These individuals reported greater levels of disability and fewer were categorized as being independent (see means in Table 1). Moreover, a greater proportion of participants in the low resilience group as opposed to the high resilience group were categorized as having a moderate, severe, or total levels of dependence (see Figure 4).

Table 1. Differences between participants with high and low resilience.

Characteristic	High Resilience		Low Resilience		Range	F	Sig.
	M	SD	M	SD			
Demographic Variables:							
Age	65.01	6.57	64.31	5.83	0 - ~	2.32	$p = .028^*$
Gender	1.80	.40	1.76	.43	0 - 1	2.40	$p = .122$
Education	13.62	2.49	13.34	2.60	5 - 13	2.25	$p = .134$
Financial security	2.05	.51	2.22	.53	1 - 3	19.27	$p < .001^*$
Lifestyle and Participation:							
Domestic participation	15.47	4.67	13.31	5.26	5 - 20	34.12	$p < .001^*$
Outdoor participation	13.75	4.02	11.87	3.92	5 - 20	41.47	$p < .001^*$
Leisure participation	13.28	3.10	11.41	2.86	5 - 20	72.29	$p < .001^*$
Total participation	42.50	9.95	36.59	10.16	15 - 60	63.15	$p < .001^*$
Disability	80.47	22.96	72.74	25.66	0 - 100	18.28	$p < .001^*$
Diet	9.64	3.32	9.27	3.17	0 - 15	2.36	$p = .125$
Physical activity	12.40	10.01	8.63	8.59	0 - 54	30.45	$p < .001^*$
Social support	92.54	12.39	76.15	16.46	15 - 105	224.90	$p < .001^*$
Perceived health status	62.54	23.38	48.95	23.07	0 - 100	62.94	$p < .001^*$
Physical and Mental Health:							
Physical impact	51.06	19.91	61.51	18.74	20 - 100	53.89	$p < .001^*$
Psychological impact	17.95	7.51	23.60	7.74	9 - 45	99.96	$p < .001^*$
Total impact	69.01	25.27	85.10	23.64	0 - 100	79.89	$p < .001^*$
Anxiety symptoms	4.65	3.36	7.30	3.80	0 - 21	98.47	$p < .001^*$
Depression symptoms	3.93	2.84	7.41	3.35	0 - 21	225.41	$p < .001^*$
Life stress	4.20	1.27	3.65	1.18	1 - 6	37.43	$p < .001^*$
Alcohol consumption	2.29	3.88	2.32	4.64	0 - ~	.01	$p = .926$
Smoking	1.30	0.61	1.25	0.62	0 - 2	1.15	$p = .284$

M - Mean SD - Standard Deviation Sig. - Significance level

Figure 3. Differences between participants with high and low resilience and level of participation in domestic, leisure, and outdoor activities.

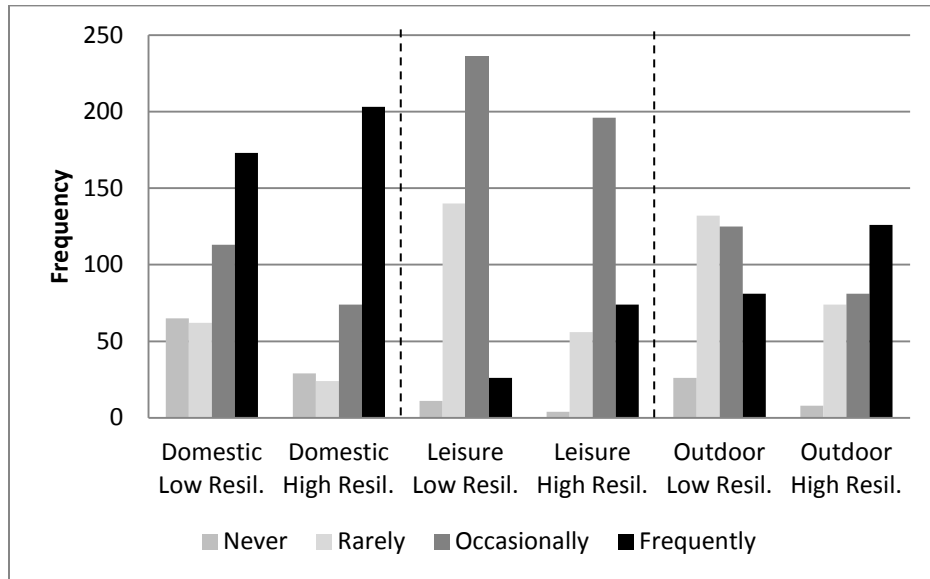
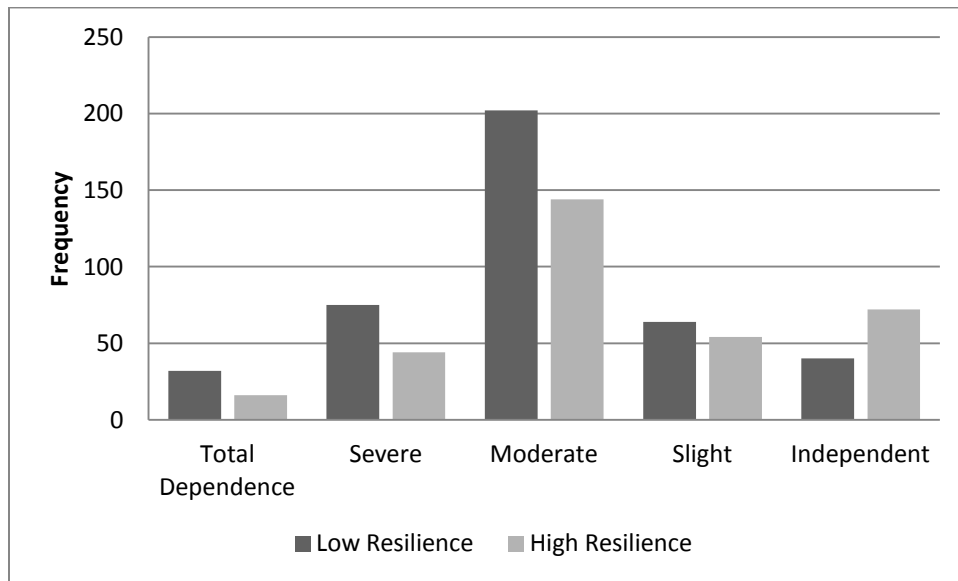


Figure 4. Disability categories of participants with high and low resilience.



Results of the ANOVA test revealed that resilience scores were significantly different in the high resilience and low resilience groups ( $F = 1108.54, p < .001$ ). Participants in each group differed from each other on all predicted characteristics except financial security. Individuals in the high resilience group scored significantly higher on domestic, outdoor and leisure activities

and FAI total, BI (indicating greater independence), age, physical activity, life stress (indicating less stress), social support, and perceived health status. Highly resilient individuals also scored lower on income, anxiety, depression, physical and psychological components of the MSIS-29, and MSIS-29 total (indicating less impact of MS; see Table 1). There were no differences between groups in terms of gender, education, diet, alcohol consumption, or smoking (see Table 1).

**The influence of resilience on participation.** Level of disability accounted for 54.2% of the variance in participants' FAI scores ( $p < .001$ ). Evidence of a moderating effect was found, in which resilience added 3.1% unique variance to the prediction ( $p < .001$ ; see Table 2). This model includes 99.19 % of the data (six cases excluded). Each of the five subcomponents of resilience contributed a small but significant proportion of variance to the relationship between disability and participation supporting a moderating effect. Only the proportion of variance added by self-reliance was greater than the variance accounted for by resilience as a total score (0.3%). Thus, overall resilience was the better predictor of daily participation than the subcomponents of resilience.

Table 2. The moderating effect of resilience on HRQOL and participation.

	Regression ( $R^2$ ) Model Statistics		
	Step 1 (Disability)	Step 2 (Disability + Resilience)	$R^2\Delta$
HRQOL:			
MSIS-29	.329*	.386*	.057*
VAS	.091*	.162*	.072*
Participation:			
FAI	.542*	.573*	.031*

$R^2\Delta$ -  $R^2$  change

\*  $p < .001$

**The influence of resilience on HRQOL.** Looking at each of the HRQOL variables, disability had the greatest impact on individuals' MSIS-29 scores, accounting for 32.9% of the variance ( $p < .001$ ). When resilience was added to the regression analysis, evidence of a moderating effect was found, with resilience contributing 5.7% unique variance to the total variance ( $p < .001$ ; See Table 2). Looking at the VAS, disability explained 9.1% of the total variance ( $p < .001$ ). Resilience also moderated this relationship, adding an additional 7.2% significant variance ( $p < .001$ ). Both of these models fit the data very well and included 741 of the 743 (99.73%) cases. Each of the five subcomponents of resilience contributed a small but significant proportion of variance to each of these variables, thereby supporting a moderating effect. Existential aloneness was the only subcomponent to add a greater proportion of variance (0.3%) than total resilience on the VAS. Therefore, composite scores of resilience were stronger predictors of both HRQOL variables.



## Chapter Four

### Discussion

Multiple Sclerosis is an unpredictable neurological disease which interferes with an individuals' ability to participate in daily activities and has profound effects on HRQOL. According to the Wilson Cleary Model (see Appendix A), personal and environmental factors can influence how disease-related impairments impact disability and how disability affects participation and HRQOL. Resilience is one personal characteristic which has the potential to modify how one copes with MS in the long term. This current study utilized a unique sample of 743 older Canadians with MS to determine the effect of resilience on healthy aging (i.e., HRQOL and participation in life roles). As expected, results showed that resilience is important for healthy aging with MS. These results along with the demographic, health, and lifestyle, and participation characteristics associated with higher levels of resilience are discussed below.

**Resilience modifies the relationship between disability and HRQOL.** Disability, measured using the BI, is strongly predictive of HRQOL, although the strength of the relationship depends on which HRQOL measure is analysed. Not surprisingly, disability is a much stronger predictor of the impact of MS on daily activities ( $R^2 = 0.33$ ; measured using the MSIS-29) than overall perception of health status ( $R^2 = 0.09$ ; measured using a visual analogue scale). Resilience explains about 6% and 7% of variance, in addition to disability, on the MSIS-29 and the VAS, respectively. Stated in another way, the MSIS-29, used to assess the physical and psychological impact of MS, is ability/disability based, as it includes questions on respondents' ability to grip or carry things and problems with balance so it is not surprising that scores are predicted by a measure of disability. The VAS, on the other hand, measures participants' perceptions (i.e., how they think and feel) about the effects of their disease on their

overall health. Resilience explains a greater proportion of the variance when perceived HRQOL was measured using VAS. These findings suggest that resilience has a stronger role to play in modifying one's perception of disability rather than the impact of the disability per se. Several researchers including Milam (2006) described earlier, have described how people who have adapted to chronic disease and disability perceive their overall health as being very good. This discrepancy between self-reported QOL and functional impairment is referred to as the 'disability paradox' (Albrecht & Devlieger, 1999).

Few studies have investigated the impact of resilience on HRQOL. Riazi et al.'s (2004) study is the only one to include individuals with MS or any form of chronic illness. Riazi et al. (2004) investigated self-reported health status and self-efficacy (i.e., one of the positive psychological attributes associated with resilience) among individuals with PPMS. They found self-efficacy to be associated with improved physical and psychological impact of MS similar to the MSIS-29 scores obtained in this study. The current study examines the impact of MS among older individuals with less progressive forms of the disease, and therefore, adds to our understanding of resilience and its positive influence on HRQOL.

This study's findings support the idea that resilience aligns well with the concept of a survivor attitude, described by author Florence Strang as a combination of one's attitude and behaviours with regard to overcoming challenges associated with having a chronic illness. Although the concept was initially constructed around cancer survivorship, Strang describes this attitude as a choice to stay positive throughout the illness experience and to make positive changes in all aspect of one's life. The VAS measure used in the present study captures the essence of this attitude as it assesses an individual's perception of his/her health and illness experience as opposed to their actual level of disability. Although the effects of resilience found

in the current investigation study were relatively small, they open the door to further investigations of other concepts such as a survivor attitude that describe the challenges and triumphs faced by persons with MS.

**Highly resilient participants reported less disability.** In the present study, participants in the high resilience group reported greater independence (i.e., less disability) in their ability to complete IADL/ADLs compared to individuals in the low resilience group. Participants in the high resilience group also participated more frequently in outdoor, leisure, and household activities compared to participants in the low resilience group. Despite these findings however, it is not clear whether level of disability negatively influences resilience or if lower levels of resilience decrease individuals' positive health behaviours, which indirectly influence level of disability.

These results are comparable to those reported by Manning, Carr, and Lennox (2014), who found that resilience moderated the relationship between chronic illness and later disability in a similar sample of aging adults. McCabe and O'Connor's (2012) findings on coping strategies used by participants with various neurological conditions, including MS, are also similar to the results obtained in the current study where individuals with higher levels of adjustment (i.e., higher resilience) were more likely to use coping strategies that involved participating in domestic, leisure, and outdoor activities. McCabe and O'Connor's (2012) study, however, leaves some questions related to the coping strategies used by older individuals with MS unanswered as the proportion of individuals 55 years of age and older with MS was unclear. The results obtained in the current study related to higher levels of resilience and participation could have also been due to the fact that participants were less disabled.

In addition to frequently participating in household, outdoor, and leisure activities, participants in the high resilience group engaged in physical activity more often than participants in the low resilience group despite limited evidence of a relationship between resilience and level of physical activity, including studies on healthy older persons (i.e., without MS or chronic illness). Perna et al. (2012) found that highly resilient individuals 65 years of age and older took part in moderate to high levels of physical activity more often than individuals who were not resilient. A similar effect was found by Resnick and Inguito (2011) among adults 80 to 90 years old.

Based on this research, there appears to be a relationship between remaining active in different types of daily activities and individuals' level of resilience and possibly their level of disability. The findings of the current study which describe participants 55 years of age and older with MS, add to the existing literature on resilience and physical activity among older individuals in this population.

**Highly resilient people with MS have a higher HRQOL.** Much like the association between resilience and impact of MS described earlier, participants' perceived health status is also linked to level of resilience. Both impact of MS and perceived health status were measures of participants' HRQOL in this study. Hardy et al. (2004) found higher levels of resilience to be associated with increased ratings of perceived HRQOL amongst individuals 70 and older. Wagnild and Torma (2013) also discovered moderate-to-high levels of resilience to be related to self-rated health status in a sample of older women while Wagnild and Young's (1993) findings revealed positive correlations between resilience and self-rated physical health, and life satisfaction among community-dwelling older persons. Although these studies demonstrate a positive effect for high levels of resilience and HRQOL measured using perceived health status,

they did not include participants with MS or any other form of chronic disease. Therefore, the current study, which examines overall perception of health status at different levels of resilience among older individuals with MS, fills this gap in the literature.

**Resilience is linked to mental health.** This study provides strong evidence that resilience is linked to mental health among older persons with MS. Highly resilient individuals reported lower life stress, anxiety, and depression than individuals with low levels of resilience. These results are the first of their kind for individuals 55 and older who are living with MS and are significant given the effects of stress on the body's immune system, which is compromised when affected by MS. Wagnild and Young (1993) did find negative correlations between resilience and depression, however, these participants did not have a chronic illness. Lower levels of stress have been linked to resilience in other fields such as medicine and other groups such as survivors of childhood abuse and trauma as outlined earlier. The findings of the current study highlight the role of resilience in decreased symptoms of anxiety and depression in an aging MS population.

**Highly resilient people have strong social support.** High levels of social support were associated with highly resilient participants in the present study. Similar results were found among individuals with chronic disabilities in King et al.'s (2003) study, who identified social support as a protective factor during major turning points in their lives. Social support in the form of family and friends was also the most helpful coping strategy reported by participants with various neurological conditions in McCabe and O'Connor's (2012) study. These supports were instrumental in helping maintain their current level of functioning. This is reflected in the lower levels of disability and frequent participation among highly resilient participants in this study. Although the relationship between social support and resilience has been well established

in other chronic conditions, the present study adds to these findings by looking at this association in an older cohort of adults with MS.

**Resilience does not alter health choices.** Another major finding of this study is that resilience does not seem to affect the health choices, including diet, smoking, and alcohol consumption, of older persons with MS. Significant differences between participants with high and low levels of resilience on each of the variables were not found. These results are not surprising given the limited number studies in the literature to support the expected differences. These findings do however extend the research on resilience and healthy life choices among aging individuals with MS. Others researchers may seek to investigate these relationships using alternative measures or samples for comparison.

**Highly resilient people are less financially stable.** In contrast to previous research, highly resilient individuals in this study were found to be less financially stable. Higher levels of resilience are generally associated with higher levels of income and vice versa (see Campbell-Sills et al., 2009; Wagnild, 2003). The current findings may reflect the question used to assess participants' financial stability (i.e., "Which statement best describes your financial situation?"), which only provides an estimate of level of income. A more valid and reliable measure of income might produce a result comparable to the existing literature. At the same time, this finding may provide new insights into the health and lifestyle habits of older individuals with MS. For example, individuals with lower levels of resilience may feel more financially secure as a result of less spending or choosing to save their money whereas highly resilient individuals may spend more money taking part in outdoor and leisure activities such as organized sports or travelling. Therefore, the relationship between level of resilience and financial stability should be further investigated to better understand the role of finances among individuals aging with MS.

**Resilience is not related to gender or education.** Higher levels of resilience were not associated with male participants or individuals with higher levels of education as expected. Few studies on resilience have examined gender differences, although the studies reviewed included enough male participants that a difference between males and females was expected. Differences between participants with high and low levels of resilience were not found in the present study despite a high representation of males in the sample. No studies pertaining to level of education and resilience among individuals with MS could be found in the literature for the purposes of this thesis hence findings from other populations were considered. Additional studies should be conducted to clarify whether or not differences in resilience related to gender and education exist.

**Resilience is related to age.** One final observation of this study is that highly resilient participants were significantly older than participants with lower levels of resilience. These findings replicate Lundman et al.'s (2007) and Wagnild's (Resilience Center, n.d.a) studies which demonstrated that resilience increases with age. Participants in both studies however did not have a chronic disease or condition. Thus, this study presents new information on resilience as it relates to aging with MS. These results also reinforce the idea of resilience as an individual trait that increases over time.

### **Strengths and Limitations**

There are many strengths associated with the research and findings presented above. The data represent a unique cohort of aging individuals with MS and offers new insights into the concept of resilience in this population. The data was gathered on 743 participants, representing 3% of the target population described by Ploughman and colleagues (2014). With an average age of 65, participants in this study are 10-25 years older than older people with MS examined in

previous studies (see Ploughman et al., 2014). The data quality was also good, where only 5.4 % of the data were missing. Finally, the data set included a high representation of men who are typically underrepresented in MS studies.

While this study had many strengths, some limitations to this research are noted. First, the data used in this study was collected from May 2011 to December 2012 and is therefore cross-sectional, which limits the possibility of assessing changes or measuring the effects of variables on participant outcomes over time. Because participation in the original study was voluntary, participants in this study may be biased towards those who were more likely to respond. Several of the measures used in this study relied on self-reports and are therefore, subjective. Ploughman et al. (2014) also described low sampling of individuals in nursing homes and assisted living situations. As a result, the finding may not represent this subset of individuals living with MS. The results obtained in the current study are also correlational in nature. Such results highlight the relationship one variable has with another as opposed to explaining cause and effect relationships. Thus, an individual's level of resilience may or may not determine his/her level of QOL or frequency of participation.

### **Future Research**

As noted in the limitations section above, the data used for this study was cross-sectional in nature, limiting the possibility of observing how levels of resilience of individuals 55 and older with MS changes over time. Longitudinal research would enable researchers to understand the effects of resilience on HRQOL and participation in life roles as individuals with MS get older and/or experience new or worsening MS symptoms. This type of research would also enable researchers to observe how levels of resilience change as a result of health lifestyle



choices that occur with aging. Overall, the information gathered would be valuable to our understanding of the role of resilience throughout the aging process.

A number of concepts similar to resilience, including 'taking charge' and Psychological Capital might be considered in future MS research. The concept of 'taking charge' has been described as a philosophy of living with arthritis rather than referring explicitly to disease control (McPherson, Brander, Taylor, & McNaughton, 2001). The concept emphasizes the importance of individuals who are suffering 'taking charge' of aspects of their lives that might have been taken charge of by other people (Jacobi, 2011). Although this term refers to individuals who have arthritis, it could also be applied to persons living with other illnesses such as MS. "Suffering from chronic, progressive illness does not simply mean opting out of life. . . although it may mean reframing ambitions and making some significant emotional as well as physical changes" (Jacobi, 2011, pg. 137). Thus, 'taking charge' does not necessarily mean living without the support of others but that patients remain the author or his or her own story (Jacobi, 2011). Parallels could be drawn between this concept and resilience as it incorporates a number of its characteristics that involve changing the way one thinks and feels that in turn, affects their actions or behaviours (i.e., 'taking charge').

Throne et al. (2003) investigated the concept of 'taking charge' in a group of individuals with various chronic illnesses including MS. All participants expressed an understanding that "illness was going to be part of their lives. . . and that being in control meant that they could live as normally as possible" (Jacobi, 2011, p. 137) and presumably, achieve greater QOL.

Rybarczyk et al. (2012) also talked about how an acute health event or exacerbation of a chronic illness is likely to create a significant change in an older adult's ability to participate and function in previous held roles. They concluded that resilience, much like 'taking charge', requires the

ability to identify strengths and to use creativity in fulfilling other valued roles when faced with functional losses.

Similarly, PsyCap has been defined as "an individual's positive psychological state of development that is characterized by: (1) having confidence (self-efficacy) to take on and put in the necessary effort to succeed at challenging tasks; (2) making a positive attribution (optimism) about succeeding now and in the future; (3) persevering toward goals and, when necessary, redirecting paths to goals (hope) in order to succeed; and (4) when beset by problems and adversity, sustaining and bouncing back and even beyond (resilience) to attain success" (Luthans, Youssef, & Avolio, 2007, p. 3). Each of these positive concepts were described earlier as being distinct yet conceptually linked to each other (i.e., Figure 2). Luthans et al. (2007) also notes that there is empirical evidence of convergent validity among them. "A proposed benefit of combining these similar, yet distinct capacities is that they share an underlying component or psychological resource that allows for individuals who possess higher levels of these resource capacities to perform at consistently higher levels than would be possible with higher levels of just one of these components alone" (Luthans et al., 2007, p. 223). Therefore, with its positive psychological foundation and overlap with a number of resilience characteristics and positive psychological attributes reviewed earlier, PsyCap would be an interesting concept to explore in an aging MS population as it may offer a new positive perspective and approach for understanding this experience.

Furthermore, the concepts of 'taking charge' and Psychological Capital tap into elements of a survivor attitude. Several aspects of each of these concepts, including taking ownership over one's illness experiences captured in 'taking control' and having confidence and perseverance to

succeed when presented with a challenge associated with PsyCap, embody what it means to have a survivor attitude. While the focus of this study was on resilience, its relation to survivor attitude as well as 'taking charge' and Psychological Capital warrants further investigation within the context of an older MS population.

### **Clinical Implications**

While psychological research in aging has traditionally focused on decline and disability, there has been an increasing emphasis on successful aging and the positive characteristics of people who are aging well (Smith et al., 2004). Similarly, there has been a shift from focusing on deficits and health problems to more strengths-based approaches in helping individuals with chronic illness cope with daily life challenges. A health care climate focused on positive outcomes as opposed to illness enforces the idea of helping individuals achieve greater QOL (i.e., living better) instead of just living longer. The literature on resilience and chronic disease discussed earlier also affirms the idea that individuals may benefit and even grow as a result of stressful experiences. Therefore, studying the psychological characteristics and attitudes of individuals who cope well with the challenges of aging with MS will not only provide valuable directions in the literature but will also inform for therapeutic interventions and strategies aimed at improving the physical and mental health and well-being of individuals in this population.

Furthermore, Kralik and colleagues' (2006) reconceptualization of resilience as a process of reflection might be insightful in future MS treatment. The results of Kralik et al.'s (2006) participatory action research study of an online group of participants with chronic illness suggest that resilience is a "process of reflection, learning and action focused toward overcoming adversity" (p. 199). More specifically, they found that the research group enabled participants to reconstitute a sense of identity, renewed meaning, and purpose in life, reflected the possibilities

and limitations of their illness. This approach to understanding resilience, which assumes that resilience is a skill that can be developed at different points in time, deviates the trait-based perspective used to guide this study and the assessment tool used to measure resilience (RS-14). Emerging research suggests that resilience can be learned or developed through experience or in conjunction with pre-existing traits as discussed earlier. Conceptualizing resilience in this way supports the idea of self-management programs, which have been proposed for individuals with MS (see DiLorenzo, Becker-Feigeles, Harper, & Picone, 2008; Finlayson & van Denend, 2003; Finlayson, van Denend, & DalMonte, 2005; Fong, Finlayson, & Peacock, 2006), although none currently focus on resilience. Given the positive effects of resilience uncovered in this study among older individuals with MS, resilience should be considered as a key ingredient in self-management program targeted for this population. These programs would need to be empirically tested using rigorous methods.

## **Conclusions**

This study demonstrates that older people with MS with high and low levels of resilience differ from one another on a number of characteristics, including age, financial security, level of disability, impact of MS, perceived health status, physical activity, anxiety, depression, life stress, social support, and participation in daily activities. Resilience was also found to moderate the relationship between participants' level of disability and HRQOL comprised of impact of MS and perceived health status, and participation in daily life roles. These findings have implications for improving the lives of individuals with MS as they progress from middle age into retirement and beyond and highlight potential targets for health and community interventions. For example, getting individuals involved in activities or groups that would increase interpersonal connections with others or improve upon existing relationships with friends and family may increase their

level of resilience. This is important, particularly at a time when interests and activity levels are changing, because level of resilience is associated with perceived disability in this population. Learning that higher levels of resilience are related to greater HRQOL and decreases in stress, anxiety, and depression might also motivate individuals to think more positively in their day-to-day lives and be optimistic about the future.

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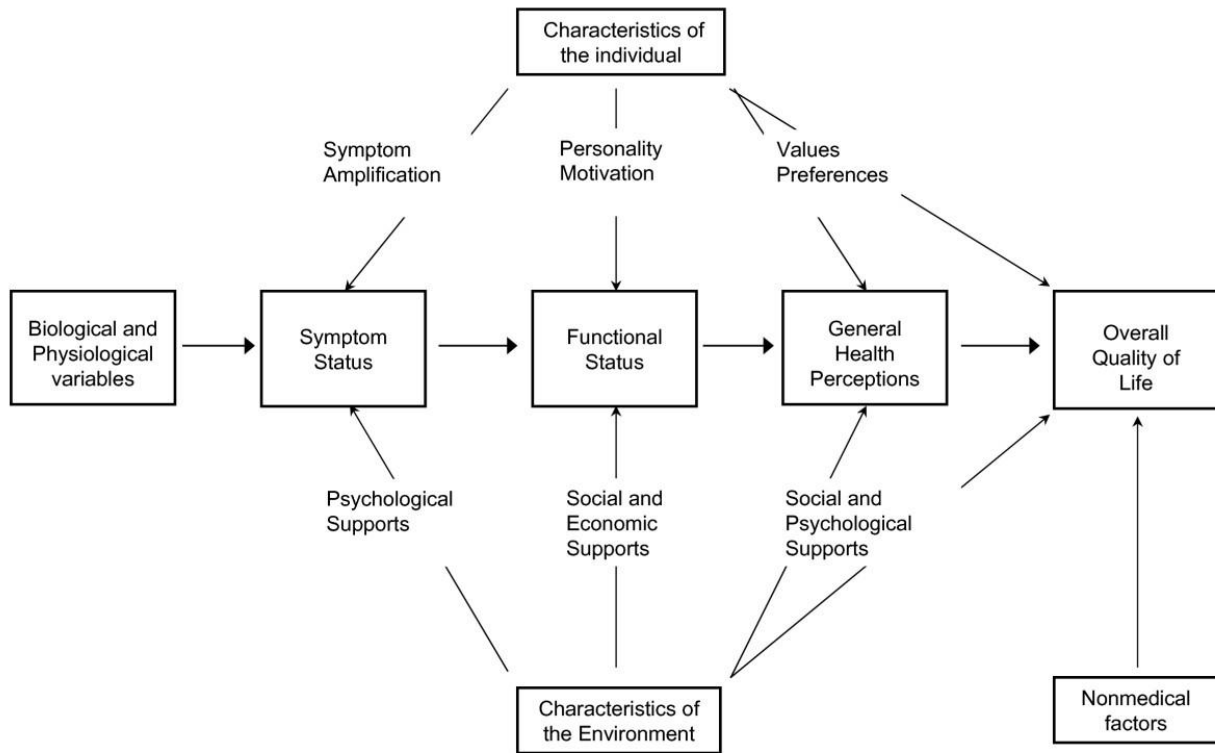
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## Appendix A

Wilson and Cleary Model for Health-Related Quality Life.



(Wilson & Cleary, 1995)