PREDICTORS OF DEPRESSION IN OLDER ADULTS WITH MULTIPLE SCLEROSIS

by

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Dedication

Dedicated to the memories of my beloved grandmother, *Didai (*1939 – 2017)

You were so kind and forgiving, and I miss you.

আমার হিয়ার মাঝে লুকিয়ে ছিলে

দেখতে আমি পাই নি।

-রবীন্দ্রনাথ ঠাকুর

Abstract

Canada's growing population of older people with MS (PwMS) has warranted a closer look into factors associated with depression that may interfere with healthy aging. At the same time, researchers, clinicians, and medical professionals treating PwMS with mood disorders have spoken about the difficulty they face when having to determine a diagnosis of depression in this population. This difficulty arises because both MS and depression share various psychological and neurological symptoms (e.g., fatigue, pain, sleep difficulties, psychomotor retardation, and cognitive difficulties). It is also found that these overlapped symptoms vary when completing a self-report measure of depression, versus when medically diagnosed by a psychiatrist. As such, we aim to investigate the personal and disease-related factors that are associated with self-reported depressive symptoms and medically diagnosed depression (i.e. depression diagnosed by a medical professional). Following this, we aim to determine the risk factors for depression in older PwMS.

This study used secondary data collected from the original study, the Canadian survey of health, lifestyle, and aging with multiple sclerosis. Data of the original study was collected from 743 Canadians (> 55 years of age and living with MS for >20 years). In this present study, presence of self-reported depressive symptoms was defined as a score of ≥ 8 on the depression component of the Hospital Anxiety and Depression Scale (HADS-D). Presence of medically diagnosed depression was determined by the item that asked participants if they have received a diagnosis of depression by their medical professional. Logistic regression was used to identify variables that predicted depression.

Self-reported depressive symptoms were found in 30.5% of the population, while medically diagnosed depression was found in 25.7%. 11.7% of PwMS had both self-identified depressive symptoms and were diagnosed with depression by their medical professional. Low social support, high perceived disability, and additional comorbid physical conditions were independent predictors of depression in older PwMS in our cohort.

Depression is prevalent in older PwMS. Clinicians should be cognizant of the overlap of symptoms between MS and depression and should employ possible ways to minimize over-diagnosing or underdiagnosing depression in this population. Identifying risk factors for depression is imperative because at-risk individuals may be thoroughly assessed for depression and will be able to receive treatment more promptly.

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List of Acronyms

ADL	Activities of Daily Living
APA	American Psychological Association
BI	Barthel Index
CCHS	Canadian Community Health Survey
CNS	Central Nervous System
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
HADS	Hospital Anxiety and Depression Scale
HADS-D	Hospital Anxiety and Depression Scale-Depression Component
HRQoL	Health-Related Quality of Life
MS	Multiple Sclerosis
MSIS	Multiple Sclerosis Impact Scale
PRQ	Personal Resource Questionnaire
PwMS	People with Multiple Sclerosis
QoL	Quality of Life
WHO	World Health Organization

Chapter 1

1.1 Statement of the Problem

The almost irrefutable hypothesis that people with chronic diseases are more

vulnerable to depression continues to grow in popularity (Gunn, Diggens, Hegarty, &

Blashki 2006; Huang, Dong, Lu, Yue, & Liu, 2010; Katon, 2011; Kuo, Tran, Shah, &

Matorin, 2015). Multiple Sclerosis (MS) is one such chronic progressive disease of the

Central Nervous System (CNS). It is comprised of inflammation, demyelination, and

axonal degeneration that can create a wide array of symptoms including physical,

psychological and cognitive difficulties (Achiron et al., 2013). The author also stated that

the progression of the MS symptoms, however, is somewhat unpredictable and often

leads to irreversible functional impairment. Depression is the most common mental health

problem in primary care settings especially among people with a chronic illness (Beal,

Stuifbergen, & Brown, 2007; Huang et al., 2010; Lynch-Jordan, Sil, Bromberg, Ting, &

Kashikar-Zuck, 2015). In addition, depression may reduce the likelihood that individuals

with chronic illness will comply with treatments or engage in useful self-care strategies

(O'Connor et al., 2016). As such, depression is a significant concern among primary care

providers because the presence of depression may negatively impact the effectiveness of

treatment provided for the chronic illness. On a similar note, depression is the most

common psychiatric condition in older people with MS (PwMS) (Feinstein, Magalhaes,

Richard, Audet, & Moore, 2014; Guhne, Stein, & Riedel-Heller, 2016). Various research

studies, as well as several reviews, have shown that the presence of MS makes an

individual more vulnerable to depressive symptoms (Feinstein et al., 2014; Mrabet, Ben

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Ali, Kchaou, & Belal, 2014; Siegert & Abernethy, 2005). Most research studies, however, focused on individuals who were recently diagnosed with MS (Hind et al., 2014; Janssens et al., 2003; Nourbakhsh, Julian, & Waubant, 2016). This is because the symptom severity and the disease course are more unpredictable in nature when MS is recently disganosed. Unpredictability often leads to depression. As such, conventionally, it is more apporpriate to have recenty diagnosed individuals as reseach population. Additionally, MS researchers report that depression negatively affects MS symptoms and exponentially increases morbidity and mortality rates in PwMS (Feinstein, 2011; Wallin, Wilken, Turner, Williams, & Kane, 2006). However, not many studies have focused on the risk factors of depressive symptoms in older PwMS. Older adults in this present study are those individuals who are of age 55 years and older.

An essential aspect of treating and preventing depression in older PwMS is identifying the factors that make an individual more vulnerable to developing depression. Individuals in primary care settings often report various somatic symptoms of depression (e.g., fatigue) that may overlap with symptoms of MS and makes diagnosis of depression difficult (Gunzler et al., 2015; Tylee & Gandhi, 2005). Therefore, it is important to explore the risk factors of depression because it will assist in the screening process by primary care providers for individuals who report those risk factors. According to McGuigan and Hutchinson (2006), approximately 25% of PwMS who have depression are undiagnosed and consequently not treated. For example, fatigue or cognitive difficulties may be due to either MS or depression. However, if medical professionals are aware of the risk factors of depression in older PwMS, then, only those individuals with

the risk-factors can be more formally assessed for depression. This screening process of individuals for risk-factors of depression can save more time for the primary care provider and it will also help in providing appropriate treatment more promptly for those in need (e.g., fatigue caused by depression may be treated by psychotherapy, while fatigue caused by MS may be treated by MS specific medications). Timely treatment of depressive symptoms may ultimately help manage exacerbation of MS symptoms and promote treatment adherence (Feinstein, 2011). Limited attention is given to studying predictors of depression in older adults with MS. In a primary care setting, several lines of research showed the adverse effect of depression on the perception of one's disability wherein individuals often amplify their symptoms and perceive the symptoms as more devastating than when objectively measured by a health care professional (Becofsky, Baruth, & Wilcox, 2013; Nabolsi, Wardam, & Al-Halabi, 2015). However, studies have not explored if negative perception about one's ability or higher perceived disability is a risk factor for developing depression.

This study aims to explore the personal and disease-related factors that may predict depression in older PwMS. This research uniquely contributes to the body of literature by drawing on a nationally representative sample of Canadian older PwMS. The results will potentially lead to better facilitation of advocacy and support for the prevention, early diagnosis, and treatment of depression in older PwMS. Overall, we aim to promote healthy living and healthy aging with a chronic condition in PwMS by understanding the risk factors of depression in this population.

Chapter 2

Literature Review

2.1 Introduction to MS

Multiple sclerosis (MS) is a chronic inflammatory disease of the central nervous system (CNS). It is an autoimmune disease in which the immune system attacks and destroys the protective lining (myelin) that covers the nerves of the CNS. This process is called demyelination (National MS Society, 2015). Demyelination of nerve fibres causes sensory and/or physical (e.g., poor sight, bladder function and bowel movement), motor (e.g., tremor, poor coordination, loss of sensation, pain, and fatigue), mental, and/or emotional (e.g., cognitive difficulties, depression anxiety, and pathological weeping and laughing) impairments (Haussleiter, Brune, & Juckel, 2009). Some symptoms remit during the early stages of the disease, and later, most PwMS undergo chronic progressive deterioration of their symptoms. The remitting and relapsing processes are often unpredictable and may lead to irreversible functional disabilities (Achiron et al., 2013).

According to Hooper (2011), there are mainly four different types of MS that individuals can be diagnosed with: relapsing-remitting MS (RRMS), secondary-progressive MS (SPMS), primary-progressive MS (PPMS), and progressive-relapsing MS (PRMS). The classifications of these four categories are based on how far the disease has progressed over time in each individual. According to the public information catalogue published on the National MS Society by Hooper (2011), RRMS is the most common type of MS with approximately 85% of PwMS being diagnosed with this type. In this

type of MS, the symptoms first appear, and then partially or fully remit before they are

followed by an acute relapse. The severity of symptoms does not worsen between the

relapse phases, and MS does not progress. The second type, SPMS, is the second phase of

RRMS. Half of the people with RRMS eventually transition into SPMS 10 to 20 years

after their MS diagnosis (Tremlett, Yousefi, Devonshire, Rieckmann, & Zhao, 2009).

SPMS is characterized by fewer recoveries of symptoms following attacks, and a gradual

worsening of symptoms between each attack leading to progressive disability.

Approximately 10% of PwMS are diagnosed with the PPMS (Hooper, 2011). In this type,

disability progresses gradually and continuously from the onset of MS without any acute

relapses. The final type of MS, the PRMS, is the rarest form with only 5% of PwMS

receives this diagnosis. It is characterized by a steady decline in symptoms from the

onset, with intermittent relapses.

MS affects approximately 2.5 million people worldwide (Beck, Metz, Svenson, &

Patten, 2005). In Canada, the rate of MS ranges between 55 and 240 per 100,000 people,

which places Canada among the countries with the highest rates (Beck, Metz, Svenson, &

Patten, 2005). Beck et al. (2005) reported that in Canada, Atlantic Provinces have the

highest rate of MS followed by the Prairies, BC, and Ontario, and Quebec has the lowest

rate of MS. The age of onset for PwMS is between 20 and 50 years with its peak at

approximately 30 years (Haussleiter et al., 2009; Ramagopalan & Sadovnick, 2011).

Various factors are found to make individuals more susceptible to MS. For instance,

genetics and familial factors, ethnic factors, with Caucasian males showing higher MS

rates than their African, Mexican, Native American, Puerto Rican Japanese, Chinese, and

Filipino counterparts (Ramagopalan & Sadovnick, 2011). Regarding environmental

factors, Ramagopalan and Sadovnick (2011) argued that, while previous studies showed a

lower risk of MS among people living close to the equator, a study conducted in

Catalonia, Spain by Otero and colleagues in 2010, and Argentina, South America by

Cristiano and colleagues in 2009 did not support the above statement. According to Ebers

(2008), studies conducted in Canada and Australia, provided substantial evidence for

several other environmental factors (e.g., latitude, sunlight, availability of vitamin D, and

photobiology) that influence the unusual geographical distribution of MS. Ramagopalan

and Sadovnick (2011), added that other factors that place individuals at a higher risk for

MS, are infection with Epstein-Barr virus (EBV), and smoking. With respect to sex

differences, it was found that MS was two to three times more common in women than

men (Pozzilli et al., 2003). Ramagopalan and Sadovnick (2011) shared their observation

on the ambiguity in understanding the prevalence of MS and noted that there were diverse

factors that make an individual vulnerable to MS and that no single factor was common

and present in all PwMS. As such, it is unlikely that one single factor or event is

responsible for MS, but instead, it develops in genetically susceptible individuals as a

culmination of individual habits and environmental exposures.

As the evolution and course of MS are unpredictable, disabilities caused by this

disease are inconsistent, but the illness is always associated with reduced activity levels

(Haussleiter et al., 2009). As such, MS poses a significant threat to the physical and

psychological well-being of individuals, often forcing them to be prepared for several

unannounced challenges. For example, a recent study conducted in a New Zealand

population with MS by Alla et al. (2016) predicted that with progressing time, the majority of PwMS would develop extensive and irreversible locomotive disability. The authors reported that the progression of MS, its uncertain course, and its irreversible symptoms cause numerous problems both on a physical and psychological level (e.g., depression). These problems may be a direct result of MS (e.g., biological causes) or due to adjustment difficulties related to the disease (e.g., psycho-social causes) (Feinstein, 1995). Secondary health concerns, both physical (e.g., hypertension, hyperlipidemia, and chronic lung disease) and psychological (e.g., depression and anxiety), are very common in MS and have a significant adverse impact on the multi-dimensional domains related to physical, mental, emotional, and social functioning known as the health-related quality of life (HRQoL) (Marrie, Reider, et al., 2015; Marrie, Reingold, et al., 2015; Nourbakhsh et al., 2016; Sahakyan, Avagyan, Avetisyan, & Manvelyan, 2013). In a review on the effects of comorbidities on MS, Marrie and Horwitz (2010) reported that psychiatric and physical conditions in PwMS produce complex interactions that have both direct and indirect negative implications on HRQoL.

The working definition of older adults by the WHO took into consideration various aspects such as social class differences and/or functional abilities related to the workforce (Kowal & Dowd, 2001). According to Kowal and Dowd (2001), most developed countries in the world have accepted the chronological age of 65 years as a definition of an older person which corresponds to the age of retirement. According to Gorman's description of old age (as cited in (Kowal & Dowd, 2001)), although a chronological age of 60 or 65 marks the beginning of old age in developed countries, it is

not the same for developing countries. He states that social constructs such as social roles and contributions also define old age. In many instances, social contributions and loss of social roles decrease due to the presence of health-related difficulties which may be attributed to a chronic illness. It is acknowledged that the working definition of older adults with a chronological age of 55 is somewhat arbitrary and introduces difficulties in comparing data with other research on older adults that recruited samples with age 65 years and above. However, in case of this present study, is also believed that 55-year old individuals with a chronic illness like MS, are a better representation of the working definition in people with chronic diseases who are functionally, physically, cognitively, and psychologically more vulnerable than older adults in the general population. Other studies on MS also used 55 plus adults as their sample population and called them *older adults* (Finlayson, 2004).

2.2 Depression and MS

Depression is a term that encompasses several depressive disorders, including major depressive disorder (MDD), and persistent depressive disorder (American Psychiatric Association, 2013). Universally, depression is the leading cause of disability and a significant contributor to the disease burden among adults in high-income countries (O'Connor et al., 2016; Wang et al., 2017). According to the World Health Organization (WHO) (2012), 350 million people worldwide suffer from depression. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) states that depression is characterized by a sad mood, loss of interest in individuals' usual activities, sleep disturbances, fatigue, irritability, reduced appetite, negative self-image, decreased

concentration and suicidal ideation (American Psychiatric Association, 2013). While a

diagnosis of clinical depression needs to fulfil specific criteria as provided by the DSM-5,

depressive symptoms, on the other hand, may be characterized by any symptoms

mentioned above along with general feelings of sadness.

Depression negatively impacts an individual's holistic well-being including their

personal, academic, occupational, interpersonal, and social activities (Mrabet et al.,

2014). Depression also poses an increased risk for suicide and is a significant determinant

of low quality of life, accounting for nearly 50% of psychiatric visits and 12% of all

hospitalizations (Kuo et al., 2015). According to Statistics Canada's 2012 Canadian

Community Health Survey (CCHS) on Mental Health report, 5.4% of Canada's

population over the age of 15 reported symptoms of mood disorder in the past 12 months.

A recent community health survey on the perceived need for mental health care in Canada

highlighted that there are high rates of unmet mental health care needs among people with

depression (Sunderland & Findlay, 2013). As such, recognizing predictors of depression

seems to be a crucial aspect of identifying and meeting mental health care needs of

community dwellers in Canada. It is noteworthy that, while a diagnosis of depression can

only be made after a thorough assessment by medical professionals with the help of

structured interview questions and self-report measures, the presence of depressive

symptoms (i.e., when not meeting full criteria for any depressive disorders as suggested in

the DSM-5) may pose similar or even greater risk to individuals as they often remain

undiagnosed.

The prevalence of depression or depressive symptoms is higher in primary care patients than in the general population (Gunn et al., 2006; Kuo et al., 2015). Depression and depressive symptoms is the most common psychiatric disorder, and it is more common in PwMS than in the general population with a prevalence rate of approximately 20 to 60% (Andrade, 2011; Feinstein et al., 2014; Marrie, Reingold, et al., 2015; Sabanagic-Hajric, Suljic, & Sulejmanpasic-Arslanagic, 2016; Zorzon et al., 2001). Another recent research study by Berrigan et al. (2016), also reported a high prevalence of depression in PwMS as they investigated the impact of physical and psychiatric comorbidities in HRQoL in PwMS. The study by Berrigan et al. (2016) was conducted on 949 PwMS from four Canadian MS centres and they found that depression was the most frequently reported concern (29%), followed by physical conditions such as hypertension (17.8%), and hypercholesterolemia (12.4%), while anxiety was reported by only 11.5% of PwMS. Most often, the above percentages merely reflect those individuals who were able to identify their symptoms and communicate them to their medical professionals. It will not be astonishing if the overall rate is much higher than what research studies estimate. The reported lifetime risk of depression in PwMS is about 20% to 50% higher than that observed in the general population, as well as, in people with other chronic illness such as arthritis, and diabetes (Beal et al., 2007; Katon & Ciechanowski, 2002; Sarisoy, Terzi, Gumus, & Pazvantoglu, 2013). A study conducted in a tertiary medical centre in Mexico City investigated 44 PwMS and 25 healthy controls to evaluate neuropsychiatric symptoms. The researchers found that nearly 95% of PwMS and 16% of the control subjects had some neuropsychiatric symptoms, the majority (79%) of which were depressive symptoms (Diaz-Olavarrieta, Cummings, Velazquez, & Garcia de la Cadena,

1999). However, the mechanisms behind the increased prevalence of depression in PwMS are controversial (Maier et al., 2015). A consensus group of experts in MS and depression reported that a combination of psychosocial, neurobiological, and disease-related factors is likely responsible for the high prevalence of depression in this population (Goldman Consensus, 2005).

Katon (2011) described a bidirectional relationship between depression and chronic illness. He demonstrated that the biological changes and negative health behaviours associated with depression worsen the chronic disease. Furthermore, he showed that the biological, physical and psychological burdens associated with chronic conditions could also amplify depressive symptoms. Apart from the high cost related to treating depression alone, Katon's research also suggested that depression worsens physical functioning, interferes with self-care, and increases the risk of mortality in this population. Over the past few decades, researchers have portrayed the significant negative impact of MS on mood (Mrabet et al., 2014). Studies also show the negative effect of depression on quality of life (QoL) in PwMS and a suicide rate 7.5 times higher than among healthy individuals (Andrade, 2011; Feinstein et al., 2014). While the pathogenesis of depression in PwMS is debatable, researchers investigating the social aspects of the impact of MS suggested that factors such as response to the disease, disability caused by the disease, prognostic uncertainty, lack of social support, unemployment, and negative coping strategies play a significant role in the prediction, development, and maintenance of depressive symptoms (Dalton & Heinrichs, 2005; Wood et al., 2013). In terms of other physical and psychiatric conditions and their impact

on mood, Berrigan et al. (2016) found that depression had an adverse effect on HRQoL in PwMS. However, the researchers also found that the impact of different physical comorbidities on PwMS was mediated by the presence of depression. Scientists have shown that depression affects physical disability as well as impacts the perception of disability which often magnifies the disease-related symptoms (Becofsky et al., 2013; Haussleiter et al., 2009; Smith & Arnett, 2013; Smith & Young, 2000). However, studies have not explored if negative perception of individual's disability is a risk factor for developing depression.

Diagnosing depression in the context of MS may pose various difficulties which candidly illustrate the challenges that healthcare professionals may face. For example, Dalton and Heinrichs (2005), reported that it is often hard to distinguish depressive symptoms that are caused by damaged nerves responsible for mood regulation from those caused by mood disorder due to adjustment difficulties because of MS. As such, it appears that healthcare professionals need to be able to distinguish a person's organic MS-specific psychopathologies, and reactive psychological symptoms due to MS. Feinstein et al. (2014) discussed various significant difficulties in depression diagnosis in PwMS in their review of the link between depression and MS. They noted that, according to the DSM-5, the persistent low mood in PwMS could be categorized under three different mood disorders, namely adjustment disorder, depressive disorder due to a medical condition, and major depressive disorder. For example, an individual's depressive symptoms could be caused by inflammation of nerve fibres which may be considered a depressive disorder due to a medical condition, while, an individual's

depressive symptoms due to psycho-social difficulties as a result of MS may be termed an

adjustment disorder. Tylee and Gandhi (2005) emphasized that, although the diagnosis of

depression is mostly confirmed by the presence of psychological symptoms, nearly two-

third of patients' clinical picture is painted by somatic symptoms, such as a lack of

energy, fatigue, and general aches and pains. Some symptoms such as fatigue, changes in

sleep patterns and appetite, poor concentration, and memory difficulty may also be

associated with neurological changes due to MS and can be mistaken as symptoms of

depression or vice-versa (Feinstein et al., 2014). The authors stated that these symptoms

may also influence the self-rating measure (e.g., the revised Beck Depression Inventory)

commonly used for depression by PwMS, which is heavily loaded with somatic

symptoms. However, in order to avoid over or under reporting of symptoms due to this

overlap, researchers use the Hospital Anxiety and Depression Scale (HADS) which

focuses more on the psychological aspect of depression rather than somatic symptoms

(Feinstein et al., 2014). McGuigan & Hutchinson (2006) reported that approximately one-

quarter of PwMS with depression are undiagnosed and untreated. Long-term undiagnosed

depression can affect the overall QoL of people, which may, in turn, worsen MS-related

symptoms (Feinstein, 2011). Very few PwMS receive treatment for major depression

from their healthcare providers, as is shown in the study by Feinstein (2002). Feinstein

found that only one-third of PwMS were being treated for major depression. Depression

is very prevalent in PwMS, and yet very few are treated for it. As such, a significant

aspect of promoting the assessment and treatment of depression is to further educate both

healthcare providers and clients about the risk factors of depression and the importance of

identifying it in a timely manner.

Although the aetiology and prevalence of depression in PwMS have received significant attention over the years, not many PwMS have participated in studies focusing on treatment for depression (Beal et al., 2007; Mrabet et al., 2014). Depression has been found to interfere with treatment adherence in general (i.e. individuals without primary or mental health problems) and in primary-care populations (DiMatteo, Lepper, & Croghan, 2000; Stein-Shvachman, Karpas, & Werner, 2013). In terms of older adults in the general population, a systematic review and meta-analysis by Cole and Dendukuri (2003) searched relevant articles published between 1966 and 2001 on older (i.e., 50 years and older) community dwellers. The review showed that according to 20 studies, risk factors for depression included disability and poor health status related to medical-illness-complicated grief, sleep difficulties, loneliness, and a personal history of depression (Cole & Dendukuri, 2003). Another review by Stein-Shvachman et al. (2013) emphasized that there are mixed results available in the literature with regards to treatment adherence in younger versus older depressed people and that the presentation and predictors of depression between the two groups also vary. The study by Katon (2011) demonstrated various difficulties that depression poses on the medical population in terms of increased risk of medical symptoms, functional impairment, the cost associated with the treatment of primary disease, and low treatment adherence. Foley, Mohr and their colleagues (as cited in (Mohr, Classen, & Barrera, Jr., 2004) p. 534) identified numerous studies that highlighted the treatability of depression through psychotherapy and antidepressant medication in PwMS (Foley et al. 1987; Mohr & Goodkin, 1999; Mohr et al. 2000; Mohr, Goodkin, Islar, Hauser, & Genain, 2001). However, because a complete cure for MS is not yet known, scientists are focusing on disease-modifying therapies of MS by delaying

or preventing long-term disability (Goodin, Frohman, Halper, Likosky, & Lublin, 2002).

As such, this study aims to provide information that will corroborate previous findings on

prevalence and predictors of depression, thereby lowering the risk of depression in

PwMS. Results of this research may also help in emphasizing the importance of giving

clinical attention to the treatment of depression. This is because a complete remission of

depression may assist in better managing MS-related symptoms (Marrie et al., 2009;

Mohr et al., 2001; Siegert & Abernethy, 2005).

2.2a Predictors of Depression in Individuals with MS

Considering depression is very common in PwMS, an essential goal of clinicians

and healthcare professionals, therefore, involves preventing and managing depression in

this population. This might be accomplished by understanding social, behavioural,

individual, and disease-related predictors of depression in PwMS (Beal et al., 2007; Hind

et al., 2014; Marrie et al., 2009). The impact of depression varies among the primary

health care population and the general population (Feinstein et al., 2014; Scott B Patten et

al., 2005; Sabanagic-Hajric et al., 2016). The aetiology and symptomatologies of

depression also vary across different age groups such that there is a more diverse

attribution of depression in the older adults than in younger ones (Gottfries, 1998). For

example, according to the study conducted by Gottfries (1998), biochemical changes in

the brain of an older person and changes in neurodegenerative disorders are one of the

many factors that add to the diversity of the cause of depression in older population. A

systematic review that looked at 43 papers on PwMS whose average age ranged from 42

to 48 years found adjustment difficulties to be a probable cause of depression in these

individuals (Hind et al., 2014). Another review of depression and MS that collected data from MS clinics, community samples, and administrative health databases in Canada, showed that individuals between ages 18 to 45 have a one in four chance of developing depression over the course of one year (Feinstein et al., 2014). When individuals are busy shaping their personal and professional goals, being confronted with a lifelong chronic disease disrupts various aspects (e.g., professional, personal, social, financial) of their life. This often leads to adverse social and psychological consequences. As such, many researchers recruit adults with a wide age range (e.g., 18 to 85 years) to be able to include those in their career-building stage as well as those who are elderly (Feinstein et al., 2014; Mrabet et al., 2014). One of the probable reasons behind choosing a younger population may be to explain the impact of adjustment difficulties and to focus on depression as a result of the various challenges faced in accommodating the demands of MS. MS research has shown several personal factors as predictors of depression in PwMS such as age, gender, employment status, and social support, as well as disease-related factors such as the type and severity of MS, number of years living with MS, presence of comorbidities, and one's functional status (Beal et al., 2007; Gay, Vrignaud, Garitte, & Meunier, 2010; Hind et al., 2014; Marrie et al., 2009; Miller & Dishon, 2006; Seyed Saadat, Hosseininezhad, Bakhshayesh, Seyed Saadat, & Nabizadeh, 2014). Most of these research studies have used a relatively young sample who were newly diagnosed with MS or have used PwMS from a wide age range (e.g., 18 years and above). However, for over two decades, few studies focused on predictors of depression among older PwMS in their pre-retirement age (e.g., 55 years and over) who have been living with MS for many years (He et al., 2013; Nourbakhsh et al., 2016; Ploughman, Harris, et al., 2015). There could

be much to be learned from this group. For example, PwMS who have been living with their disease for over 20 years may not have depressive symptoms due to adjustment difficulties as these individuals may have learned ways to cope with the challenges and may be aware of the disease patterns. As such, depression due to the unpredictable course of MS may not be a concern for these individuals. Moreover, as noted by Tremlett et al. (2009), the unpredictability of MS symptoms, its course, and its severity is mostly seen in the RRMS type which is often the initial type of diagnosis in PwMS. But, in most cases 10 to 20 years after their diagnosis, individuals transition to the SPMS type in which the symptoms of MS gradually worsen, leading to progressive disability without remission. Therefore, those PwMS who have been living with this disease for over 20 years may be depressed due to progressive disability rather than the unpredictable relapse or remission.

To achieve a healthy-aging process in older PwMS, identification of modifiable risk factors for depression is imperative. This research will attempt to identify those factors that make older adults with MS more vulnerable to depression. The results of this study may be able to inform health care professionals of the preventative measures that can be considered to manage depression, and that may also help in lowering the overall burden due to MS. From the existing literature, this study has identified various factors (e.g., gender, age, financial condition, social support, and perceived disability, number of years living with MS, physical comorbidity, early retirement due to MS, and physical disability) that may be responsible for making an older adult with MS more vulnerable to depression.

2.2a.i Age

According to Statistics Canada (2015), one in six Canadians (16.1%) was at least 65 years old in 2015, and this figure outnumbered children between zero to 14 years for the first time in Canadian history. They also noted that, by the year 2024, the 65-years-old-and-above population would account for nearly 20.1% of Canada's population. According to Warnick (as cited in (Singh & Misra, 2009)), aging is portrayed as the final stage in one's lifespan and concludes one's life cycle. However, the age group that the present study focuses on is 55 years and older which is the pre-retirement age. The retirement age in Canada is 65 years (Canada Pension Plan, 2016). As noted earlier in this paper, according to Kowal and Dowd (2001), although the chronological age of 65 years is accepted as a working definition of an older person because it corresponds to the age of retirement, in many cases, social contribution, and functional ability define old age. As this study uses a group of people who have been living with a physically disabling chronic disease, for over 20 years, the working definition of older adults is set as individuals with a chronological age of 55. Another study on PwMS also used individuals between ages 55 and 81 and called their sample "older adults" (Finlayson, 2004).

Age is an important factor in determining the onset of depression. According to a report on mental illness in Canada by the Public Health Agency of Canada (2002), in most cases the onset of depression occurs during adolescence. Loss of productivity for the patient, as well as medical and hospitalization costs incurred due to depression, are thought to be two main reasons why the Canadian economy is affected by depression (Public Health Agency of Canada, 2002). According to the Centres for Disease Control

and Prevention, the 2012 Morbidity and Mortality Weekly Report, the highest prevalence

rate of depression in general population was approximately 7% for males and 12% for

females. The age group of these individuals were between 40 and 59 compared to those

above 60 years, for whom a prevalence rate was 5% for males and 7% for females. The

younger counterparts (i.e., those between age 18 and 39 years) reported a prevalence rate

of 11% for females and 5% for males. The survey used the Patient Health Questionnaire

to assess the current rate of depression of the participants and defined depression by the

presence of symptoms for two weeks with a cut-off score of ≥10 out of a total score of 27

("QuickStats", 2012).

Research has shown depression to be one of the most frequently occurring mental

disorders in older adults and is associated with increased disability and mortality risks

(Rodda, Walker, & Carter, 2011). A review of the literature between 1990 and 2001 by

Rosenvinge and Rosenvinge (2003) suggested that nearly 10-19% of older people (i.e.,

above age 65 years) from the general population have symptoms of depression. In the

year 1992, Williamson and Schulz's research study portrayed clinical depression to be

relatively uncommon among older adults with only 4% of 60 years or older being

clinically depressed, but they also noted that the presence of depressive symptoms, on the

other hand, was much more common (as cited in (Hoffman, Hays, Wallace, Shapiro, &

Ettner, 2017)). A study on a community-dwelling cohort of older adults over age 65 years

reported a similar relationship between age and depression, with older people being more

affected by mood disorders than their younger counterparts (Blazer, Burchett, & George,

1991). In terms of depression and advancing age, most research target seniors (i.e., 65

years or older) and there are not many studies that focus on depression in older adults in

their pre-retirement age (Blazer et al., 1991; Guhne et al., 2016; Kneebone, Dunmore, &

Evans, 2003). The authors reported that older adults in pre-retirement age have unique

challenges and needs and are often faced with significant difficulties in social, physical

and psychological aspects which may be different from the elderly people. Having a

chronic condition such as arthritis, heart disease, diabetes and/or MS poses more threat to

the mental wellness in this population.

Many studies in the MS literature have used similar age ranges when describing

studies conducted on older adults. For example, an explanatory research study on health

issues and service needs with PwMS used a sample of older adults with age ranging

between 55 to 82 years (Finlayson, 2004). It is observed that while some studies reported

a higher prevalence of depression among older PwMS (Seyed Saadat et al., 2014), others

have not shown such results in MS population (Patten, Metz, & Reimer, 2000). Some

have argued that older adults (age 65 years and older) seemed to be less vulnerable to

depression which was mainly due to the fact that older adults were less emotionally

responsive (Kneebone et al., 2003). Mixed results in the literature regarding age as a

potential risk factor for depression in PwMS, seem to indicate that different aspects

account for the prevalence, development, and vulnerability to depression in different age

groups. For example, younger and recently diagnosed PwMS show signs of depression

due to their difficulties in adjustment with an unpredictable disease, poor health status

when compared to their previous condition and anticipating future disability (Janssens et

al., 2003). However, this may not be the case for older adults (age 55 to 88) who have

learned to live and cope with MS for over two decades (Ploughman et al., 2012).

Therefore, if older adults with MS have already addressed their depression related to MS

diagnosis by learning to adjust to the unpredictable disease and anticipating future

disability, then is age still a predicting factor for depression in this population?

Experience of growing old varies considerably among older adults. Therefore, for a more

accurate portrayal of significant life changes, some gerontologists have emphasized

defining sub-groups instead of lumping all older people in one group. For example, one

study used sub-grouping as young-old (65 to 74), middle-old (75–84), and oldest-old

(85+) (Zizza, Ellison, & Wernette, 2009). Although older adults in this study are those

individuals who are 55 years and over, it is acknowledged that age-related difficulties will

be different within this age group (i.e., 55 years to 88 years).

2.2a.ii Gender

According to Loue (2008), in recent times, scholars have defined gender as a

function of culture, while sex is a function of biology, unlike the traditional views where

biological sex, gender role, and social identity were linked and used interchangeably. In

Loue's book on Encyclopedia of Aging and Public Health, sex was referred with terms

such as "male" and "female," while terms like "masculinity" and "femininity" were used

to refer to gender. In the MS literature some researchers prefer to use the term "sex" to

denote the two main groups (e.g., men and women) based on the reproductive function

that categorized their target population, while others used the term "gender" (Alla et al.,

2016; Beal et al., 2007; Chwastiak et al., 2002; Magyari, Koch-Henriksen, Pfleger, &

Sorensen, 2014). As such, for convenience and to avoid changing previous authors' terms

when referring to the literature, the term "gender" and "sex" will be interchangeably used in this study. However, it must be also acknowledged that confounding factors will be associated by interchanging the words.

Epidemiological findings over decades have produced mixed results about the relationship between the prevalence of depression and gender. A survey by the Centers for Disease Control and Prevention reported a higher prevalence rate of depression in women across all ages (>12 to >60 years) ("QuickStats", 2012). Piccinelli and Wilkinson (2000) were also of the same opinion that depression is more prevalent in women than men. Females carry twice the risk of depression compared to males which also corresponded to their relapse rate (Kessler, 2006; Kuehner, 2003). Studies have shown that women tend to use more social support and friends than their male counterparts which lead to more communication about their mood-related difficulties to their friends and families, resulting in receiving treatment for depression (Dalgard et al., 2006). As such, women are seen to be more articulate when it comes to expressing their difficulties, also making it easy for healthcare professionals to provide a fast and effective treatment. Other reasons for gender disparity may be hormonal effects, genetic vulnerabilities, and the reproduction process (Dorn & Chrousos, 1997; Kooiman, Jansen, & Peeters, 2006). Leach, Christensen, Mackinnon, Windsor, and Butterworth (2008) alluded to several psychosocial, and functional factors that were responsible for the gender difference including physical health, physical activity, and perceived interpersonal and employment problems. Individual factors that make women more vulnerable to depressive symptoms

may also include different cognitive styles of processing and managing depression such as rumination (Nolen-Hoeksema, 2000).

The above view was not supported by other studies that showed higher rates of depression in men compared to women (Emslie, Ridge, Ziebland, & Hunt, 2007; Nortvedt, Riise, & Sanne, 2006). In the recent past, research focusing on men's mental health has received much attention due to the increased suicide rates in men (Hunt, Sweeting, Keoghan, & Platt, 2006). Men have a higher rate (i.e., three to seven times) of death by suicide across all ages compared to women (Nock et al., 2008). The importance of socially constructed gender roles has been an essential determinant in the experiencing and reporting of depressive symptoms (Vafaei, Ahmed, Freire Ado, Zunzunegui, & Guerra, 2016). In many societies (i.e., eastern and western), masculinity is the dominant role which reflects strength, and emotional control, which is opposite to what is expected of a feminine role comprising of vulnerability and emotional expression (McQueen & Henwood, 2002). Although gender roles are different from biological sex, it is still an important aspect that impacts the mood of male individuals. While it is more socially acceptable for women to express emotional distress, men may choose to be less articulate to prove their masculinity and as such their depression may go undiagnosed (Brownhill, Wilhelm, Barclay, & Schmied, 2005). This phenomenon of depression and gender role were also well documented by Vafaei et al. (2016) who reported that older adults with androgynous life roles reported lower rates of depression. In other words, men or women who are not strict followers of gender roles according to social expectations may be less affected by depression because of lack of gender-related tasks as defined by the society.

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According to Loue (2008) gender role refers to what individuals do or how they communicate with others and to themselves that would suggest they are males, females, transgender, or androgynous.

Studies showed that in primary care settings, female patients reported more psychological impairment than male patients (Di Marco et al., 2006; Magyari et al., 2014). On the other hand, functional and occupational impairments were reported to be significant challenges for males (Alla et al., 2016). Research findings in PwMS, show mixed results whereby some studies supported the association between female gender and depression, and other studies reported that gender was not a significant predictor of depression (Alsaadi et al., 2015; Beal et al., 2007; Patten et al., 2000; Zorzon et al., 2001). Not many studies have particularly focused on gender or sex being a vulnerability factor for depression in older PwMS. Therefore, results from this present study will be an important contribution as it aims to examine if sex is a risk factor for depression in older PwMS, and if so who is more vulnerable?

2.2a.iii Social Support

Various social, economic, geographical, relational, and cultural facets make up social support (Faramarzi et al., 2015). It can be comprised of an individual's significant other, friends, families, colleagues, and neighbours. From a healthcare perspective, Cobb (1976) defined social support as follows:

Social support is conceived to be information belonging to one or more of the following three classes: 1. Information leading a subject to believe that he is cared

for and loved. 2. Information leading the subject to believe that he is esteemed and valued. 3. Information leading the subject to believe that he belongs to a network of communication and mutual obligation (p. 300).

Broadhead et al. (1983), (as cited in Grav, Hellzèn, Romild, and Stordal (2012), p. 112) noted that although social support and depression have been extensively researched since the mid-70s, not much attention has been given to the older adults (i.e., above 65 years). Depression and social support literature on older adults (e.g., 65 years and above) demonstrated that social deficits, and adverse life events are risk factors for depression in general population as well as in primary health care population (Bambara, Turner, Williams, & Haselkorn, 2011; Grav et al., 2012; Mohr et al., 2004; Prince, Harwood, Blizard, Thomas, & Mann, 1997; Wu et al., 2013). According to Grav et al. (2012), a cross-sectional survey on 40,659 individuals from ages 20 to 89 years, showed that depression was most prevalent in older men (age 75 to 89 years) who lack tangible social support. Grav and colleague used the HADS to measure depression with a cut-off score of also >8, similar to the instrument and the cut-off score used in this present study. Sonnenberg et al. (2013) portrayed gender-based differences between depression and social support noting that older men with low social support were more vulnerable to depression. Recent research has shown the increased need for social support among older adults for physical and emotional assistance, emphasizing that social interaction may strongly influence HRQoL (Benmarhnia & Zunzunegui, 2014; Khalili, Sam, Shariferad, Hassanzadeh, & Kazemi, 2012).

The need for social support and its positive impact on overall QoL have been well studied in individuals with various chronic diseases (e.g., coronary heart disease, fibromyalgia, diabetes, MS, and cancer) in primary care settings across the world (Hughes et al., 2014; Lett et al., 2005; Lynch-Jordan et al., 2015; Wu et al., 2013). Coyne and colleagues (1987 and 1991) (as cited in Mohr et al. (2004) p. 533) demonstrated that depressed PwMS in primary care settings exhibit poor interpersonal behaviours that are unappreciated by others which further lead to feelings of rejection and isolation. As such, the authors hypothesized that treating mood disorders will in turn increase social support which may have a positive impact on MS. Various studies on MS have provided similar conclusions, demonstrating the positive impact of social support on disease management, lowering emotional distress, and increasing QoL (Aghaei, Karbandi, Gorji, Golkhatmi, & Alizadeh, 2016; Costa, Sa, & Calheiros, 2012; Mohr et al., 2004). In older adults (age 55 to 85 years) with MS, the chronic condition decreases their ability to participate and engage in activities to a significant extent (Beekman et al., 2002). A small chore that seemed manageable before may now look like a big task, inhibiting many PwMS from participating in such activities. This may also include attending community organizations, places of worship, and/or attending appointments with health care professionals which may negatively affect one's enthusiasm to live a fulfilled life with a chronic illness. A Canadian study by Hystad and Carpiano (2012) noted a strong association between community-belonging and health-behaviour suggesting that social belongingness is an essential factor that is considered when formulating health prevention strategies. Therefore, form the above studies it appears that lack of social support is one of the most significant risk factors for depression. As such, adding social support as a potential

predicting factor for depression in older PwMS is an essential aspect of this research study.

2.2a.iv. Financial Condition

According to the American Psychological Association (APA), socioeconomic status is often measured as a combination of income, educational level, and occupation and is viewed as the social class of an individual. Financial condition, on the other hand, is the availability of monetary resources regardless of an individual's social standing. Financial condition may not be the same as socio-economic status. According to Butterworth, Rodgers, and Windsor (2009), financial challenges usually determine individuals' difficulties with providing basic necessities for themselves, their family or other dependents. A study conducted in New Zealand on college students reported that young students who were faced with more financial difficulties were psychologically more distressed (Chongpison et al., 2015). On the other hand, an older study by Mirowsky and Ross (1999) reported that older adults are less prone to financial distress as they are thought to better cope with hardships through life experiences. Research in general population showed that both low socio-economic status and poor financial condition contribute to stress and depression (Butterworth et al., 2009; Lorant et al., 2007; Vinokur, Price, & Caplan, 1996; Wang, Schmitz, & Dewa, 2010).

Having a chronic disease is associated with significant financial burden and deprivation (Jeon, Essue, Jan, Wells, & Whitworth, 2009). For example, researchers highlighted that for people with a chronic disease, factors such as regular healthcare services, frequent absenteeism from work, unemployment, and early retirement might

worsen existing difficulties that are posed by the disease. Jeon et al. (2009) reported that affordability of medical treatments promotes self-management and risk reduction behaviours which are important aspects to consider when dealing with chronic diseases. According to Butterworth, Olesen, and Leach (2012), an individual with a poor financial condition is more vulnerable to depression than those who were previously diagnosed with depression. Therefore, an individual without any prior depressive symptoms may be at risk of developing depression due to financial hardships because of expenses incurred from the treatment of a chronic disease, and/or job loss due to the chronic disease. Constant financial hardship due to the medical expenses related to a chronic illness may prevent individuals from seeking further medical help in fear of worsening their financial condition. Such a vicious cycle of rejecting medical assistance due to financial struggle can, in fact, exacerbate the medical condition, eventually incurring more expense.

Lange and Byrd (1998) examined the impact of perception of financial distress on feelings of psychological well-being. They reported that daily financial stress was negatively associated with the perceptions of an individual's capability to manage and control their financial condition which ultimately was directly linked with an individual's levels of psychological well-being (Lange & Byrd, 1998). Another research study conducted on 576 long-term renal cancer survivors in primary care settings demonstrated that depression was associated with a greater perception of financial burden (Chongpison et al., 2015). As such, from the studies by Chongpison et al. (2015), and Lange and Byrd (1998), it appears that the perception of "not having enough money" is also associated with psychological distress.

Studies on PwMS have not specifically investigated the impact of perceived financial status on depression. Instead, studies have focused on the effects of socioeconomic status on depression suggesting that lower socioeconomic status was associated with an increased risk of having depression, undiagnosed depression, and untreated depression (Marrie et al., 2009). Research investigating income level in PwMS found lower levels of income in 916 households with MS in a cross-sectional study conducted in the UK (Green, Todd, & Pevalin, 2007). Another cross-sectional study conducted by Kobelt, Berg, Lindgren, Fredrikson, and Jonsson (2006) in nine European countries found that 60% to 75% of PwMS (N = 13,186) with an average age ranging from 45.1 to 53.4 years who have been living with MS for over 18 years, were without a job. They also reported that expenses in the household increased with worsening of MS symptoms. In PwMS, Orlewska et al. (2005) reported that an individual's productivity loss further adds to the expense that has already been incurred with MS which increases the overall economic burden. Thus, it appears that although there is apparently a relationship between financial conditions and psychological distress, several factors seem to play a role in determining if a poor financial condition is a risk factor for depression in older PwMS. Therefore, financial condition is believed to be an important addition to the list possible risk factors that may make older PwMS more vulnerable to depression.

2.2a.v Number of Years Living with MS diagnosis

Number of years that an individual is living with the formal diagnosis of MS by his/her neurologist is defined by the "number of years living with MS" in this study. The concept of healthy aging with MS is a relatively new one because the peak prevalence of

MS has shifted over the past 20 years, from about 40 years of age to 50 years of age (Marrie, Yu, Blanchard, Leung, & Elliott, 2010). This is partly because of early diagnosis of MS, better treatment availability, and improved longevity of PwMS (Marrie et al., 2010). This means that older PwMS can continue to live a meaningful and satisfying life even with a chronic disease like MS. However, many researchers have demonstrated that greater length of MS or longer time since MS diagnosis is connected to several disease-related impairments (e.g., fatigue, disability) and psychosocial deficiencies (e.g., cognitive difficulties and mood disorders) which may impact their QoL (Achiron et al., 2013; Alla et al., 2016; Sahakyan et al., 2013). Fatigue, a common symptom of both MS and depression has been widely researched as a symptom that worsens over time, and studies show a positive connection between fatigue and depression (Fernandez-Munoz et al., 2015; Kargarfard, Eetemadifar, Mehrabi, Maghzi, & Hayatbakhsh, 2012; Sabanagic-Hajric, Suljic, & Kucukalic, 2015). Research has also shown that this positive relationship between fatigue and depression in PwMS can be further mediated by advancing age and physical disability (Azimian, Shahvarughi-Farahani, Rahgozar, Etemadifar, & Nasr, 2014; Garg, Bush, & Gappmaier, 2016). In a study with 1,500 PwMS, Achiron et al. (2013) showed that cognitive decline is associated with the duration of MS. Cognitive difficulties, like memory, attention, and concentration, are also some of the known symptoms of depression (Richard et al., 2013). According to Moore et al. (2012), variation in depression levels was associated with MS relapse and then at 2 months and 6 months thereafter. A 6-month longitudinal study of 132 people with relapsing-remitting type MS, who were administered the HADS at the time of relapse and at the 2-month and 6-month period, revealed that almost 50% of PwMS scored above the threshold (i.e.,

HADS score ≥8) indicating the presence of depression during the assessment. The results

also demonstrated that even though rates of physical disability as measured by the

Expanded Disability Status Scale (EDSS) improved suggesting remission from MS,

levels of depression remained high at 6 months indicating that a portion of PwMS did not

recover from depression. It appears from the above studies that length of MS has some

direct or indirect association with depression.

Other authors claim that disability, and cognitive and emotional difficulties faced

by PwMS are independent of the duration of MS (Moller, Wiedemann, Rohde,

Backmund, & Sonntag, 1994; Ploughman et al., 2012). A recent study conducted with 39

PwMS and 39 healthy controls reported that adaptive coping skills alleviate mood swings

in people with clinically isolated syndrome (i.e., another form of MS) and RRMS

(Bianchi et al., 2014). The researchers also noted that older adults who have been living

with MS for a long time may have learned adaptive coping strategies and have more

experience with disease management which may act as a protective factor against

developing depression due to adjustment difficulties. Similar opinion was also expressed

by Ploughman et al. (2014). Other studies that did not find a correlation between years

living with MS and depression corroborated the above finding (Arnett et al., 1999;

Feinstein & Feinstein, 2001; Zorzon et al., 2001). An older study by Rao, Leo, Bernardin,

and Unverzagt (1991), showed that there was no significant relationship between

cognitive deficiency and MS duration, depression, MS course, or medication usage.

The mixed findings in this area support the need to re-consider length of MS or

number of years living with MS as a potential predictor of depression in older PwMS.

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2.2a.vi Disability

According to the definition of disability by the World Health Organization (WHO), disability is more than just an individual's physical or mental health problems; it is an intricate interaction between an individual's physical body and his/her societal aspects (World Health Organization (WHO), 2002). Several research studies demonstrated the impact of physical disability on depression and vice versa in the general population as well as in people in primary care settings (Garg et al., 2016; Oremel, Vonkorll, & Brink, 1996; Smith & Arnett, 2013). Studies have also found a close association between depression and perceived disability indicating that mood disorders often magnify somatic symptoms (e.g., pain and fatigue) giving individuals an impression that they are more disabled than when assessed by their physician (Menendez et al., 2015; Walsh & Radcliffe, 2002). However, the risk factors of depression in terms of physical disability and perceived disability are not yet demonstrated. Moreover, studies have not examined which aspect of disability (physical or perceived) is more threatening to developing depression in older PwMS.

2.3a.vi (a) Physical Disability

Disability is an overarching term that suggests impairment (i.e., difficulty in physical function or structure), activity limitation (i.e., obstacles encountered by a person engaging in tasks), and participation restriction (i.e., difficulties faced by individuals when involving in activities of daily living (ADLs)) (WHO, 2017). According to the explanation provided on the official website of the Government of Newfoundland and Labrador for Education and Early Childhood Development, individuals with a physical

disability are those who have an acquired or congenital physical and/or motor impairment

(Government of Newfoundland and Labrador, 2017). Physical characteristics of disability

may include, paralysis, altered muscle tone, an unsteady gait, loss of, or inability to use,

one or more limbs, difficulty with gross-motor skills, and difficulty with fine-motor skills.

Several research studies provided longitudinal evidence portraying a bidirectional

relationship between physical disability and depression (Beekman et al., 2002; Oremel et

al., 1996; Penninx, Leveille, Ferrucci, Van Eijk, & Guralnik, 1999; Von Korff, Ormel,

Katon, & Lin, 1992). Researchers have found an association between physical disability

and depression in other medical conditions, such as fibromyalgia, cancer, and arthritis

(Geisser et al., 2008; Hackett & Anderson, 2005; Roh et al., 2012; Smeets, 2009). In

terms of older adults, Geerlings, Beekman, Deeg, Twisk, and Van Tilburg (2001)

conducted an eight-wave prospective community-based study that investigated the

longitudinal effect of depression on functional limitations and disability on people with

chronic physical diseases. Geerlings' study also had a comparable age group (i.e., 55-85

years) to the present study. The sample of Geerlings' study consisted of 325 non-

depressed and 327 depressed people. The researchers found a significant longitudinal

association between depression and functional limitations due to physical disability.

Following a review of several research studies it was noted that in PwMS,

physical disability and fatigue were thought to be the result of pathophysiological

mechanisms such as inflammation, demyelination, axonal loss, and neuroendocrine

dysregulation (Bol, Duits, Hupperts, Vlaeyen, and Verhey, 2009; Kos, Kerckhofs, Nagels,

D'Hooghe M, & Ilsbroukx, 2008). According to Haussleiter et al. (2009), in PwMS, the

demyelination of nerve fibres causes physical and psychological impairments that are generally irreversible in nature. While some symptoms remit during the early stages of MS, the symptoms may later relapse with greater severity and this process is often unpredictable and results in functional disabilities (Achiron et al., 2013). Research provided mixed results when demonstrating the association between depression and disability in PwMS. While some found a positive relationship, reporting greater physical disability resulting in depression (Feinstein & Feinstein, 2001; Smith & Arnett, 2013; Zorzon et al., 2001), others could not support the same from their research study (Arnett et al., 1999; Berg et al., 2000). Lynch, Kroencke, and Denney (2001) studied the relationship between disability and depression in 188 PwMS and found that disability was an independent predictor of depression. When other psychological factors such as uncertainty, hope, and emotion-centred coping were added to disability, together, the variables accounted for approximately 40% of the variance in individual's self-reported symptoms of depression. Another study, conducted in the UK, with 4516 PwMS found that the percentage of people experiencing depression increased with a physical disability such that 17.1% of people with low, and 71.7% with a high disability experienced at least mild depression (Jones et al., 2014). In a study, Sabanagic-Hajric et al. (2016) examined the relationship between disability and depressive symptoms in 120 PwMS in an acute relapse phase and found a moderate correlation between disability and somatic symptoms of depression in older adults compared to younger ones. According to Alla et al. (2016), the age of an individual, age at onset of MS, and years living with MS are independently associated with physical disability noting that with the progression of the above variables, disability of the individuals worsens. Gilchrist and Creed (1994) reported that in PwMS,

social stress is commonly associated with depression which they think may apparently be linked with individual's physical disability including several other factors such as unemployment, financial, and interpersonal problems.

A recent study that explored the relationship between physical disability, physical activity and depression in 27 PwMS found that higher levels of disability were significantly associated with more symptoms of depression (Sadeghi Bahmani et al., 2017). The researchers also reported that physical activity levels did not mediate the effect of disability on depressive symptoms. While some studies show disability to be independently associated with depression, other studies demonstrated that there was no relationship between physical disability and depression. Therefore, it seems pertinent to explore if physical disability is a potential risk factor for depression in older PwMS.

2.2a.vi (b) Perceived Disability

Perceived disability can be described as one's perception or views about his/or her level of disability. Can depression impact this perception of disability? Arnstein, Caudill, Mandle, Norris, and Beasley (1999) explained the complex phenomenon of self-efficacy being a determining factor in the development of disability and depression in individuals with chronic pain. According to Bandura (as cited in (Marcus, Selby, Niaura, & Rossi, 1992) p. 61), self-efficacy means the confidence in one's ability to carry out a certain behaviour, and it is associated with one's actual execution of the behaviour. Therefore, an individual's perception of his/her disability will also determine if he/she can physically perform a certain task regardless of their level of physical disability. In a study conducted on patients in a shoulder clinic, Menendez et al. (2015) stated that catastrophic thinking

and low self-efficacy were associated with greater shoulder pain and disability. They

concluded that psychological factors seemed to affect an individual's perception of their

pain more so than their physical pain. Similar findings were reported in people with

arthritis, wherein the perception of disability was more strongly associated with

depressive symptoms than actual physical limitations (Becofsky et al., 2013). As such,

researchers suggested that psychotherapy for depression should also focus on enhancing

patients' self-efficacy in order to deal with their perceived disability (Hainagiu, 2012).

Various studies conducted in people with chronic illness demonstrated the difficulty in

diagnosing depression especially when the somatic symptoms of depression (e.g., low

energy, pain, and fatigue) emulate the symptoms of the chronic disease (e.g., arthritis,

fibromyalgia, or MS) (Beal et al., 2007; Wolfe & Michaud, 2009). Nabolsi et al. (2015)

found an association between self-perceived fatigue and activity limitation. The authors

reported that older adults seem to restrict their participation based on the perception of

their fatigue compared to their level of fatigue as assessed by physicians. From the above

research studies, it appears that depression impacts people's perception of their disability

often magnifying the symptoms than when functionally measured by a physician.

However, no one has yet explored if the perceived disability is a risk factor for depression

in older PwMS.

In PwMS, only one study focused on the role of depression on patients' (mean age

of participants was 46 years) perception of their disability (Smith & Young, 2000). The

researchers found that according to Beck Depression Inventory and HADS cut-off scores,

depressed patients were three times more likely than non-depressed patients to perceive

their disability as being greater than the physicians' perception of the patient's disability. However, there are no studies that demonstrate similar findings among older adults with MS. As such, exploring perceived disability as a potential predictor of depression was thought to be a relevant aspect of this research study.

2.2a.vii Physical Comorbidities

According to Valderas, Starfield, Sibbald, Salisbury, and Roland (2009), comorbidity is described as the presence of more than one distinct condition in an individual. It is defined by the nature of the health condition, the relative importance of the co-occurring conditions, the chronology of the presentations of the conditions, and the complexities of the conditions with respect to morbidity risks (Valderas et al., 2009). To achieve overall progress in health, health care professionals may need to address, manage and/or treat multiple coexisting diseases, along with the primary disease (Valderas et al., 2009). Depression is a very common comorbid condition in primary health care settings (Beal et al., 2007). Various chronic diseases are associated with depression which is a major source of concern to individuals, families, and medical professionals (Becofsky et al., 2013; Chongpison et al., 2015; Lynch-Jordan et al., 2015; Wolfe & Michaud, 2009). When an individual is diagnosed with more than one chronic disease, it sometimes becomes difficult to identify which disease was responsible for the development of depression.

PwMS can be diagnosed with any number of comorbid diseases. PwMS who may not have depression may be suddenly depressed if they develop a comorbid disease during their course of MS, such as arthritis, heart disease, cancer or fibromyalgia.

Research suggests that depression caused because of a newly diagnosed comorbid disease may worsen symptoms of MS (Marrie et al., 2009). On a similar note, studies have shown that the interaction of a secondary disease and depression pose challenges in the diagnostic process and the management of all the diseases and such challenges can significantly delay detection of depression, worsen MS-related symptoms, and decrease an individual's QoL (Allison, 2007; Marrie et al., 2009). The presence of depression and/or other psychopathologies as comorbid conditions have been extensively studied throughout the literature (Anderson, Freedland, Clouse, & Lustman, 2001; Moussavi et al., 2007). Marrie and Horwitz (2010), suggest that among other factors, physical and mental comorbidities negatively impact MS by delaying MS diagnosis, increasing disability, and decreasing HRQoL. Several studies that identified the presence of depression as a comorbid condition in PwMS noted that the overall comorbid diseases are more common in older people with MS (>60 years) (Chwastiak et al., 2002; Marrie et al., 2008). However, no studies have specifically investigated comorbid diseases as a potential vulnerability factor for depression in older PwMS. It is, therefore, crucial for healthcare professionals to pay close attention to such co-occurring diseases in older PwMS as a risk factor for developing depression.

2.2a.viii Early Retirement

The CBC news reported that according to Statistics Canada, the average age of retirement of Canadians rose from 61 in 2005 to 63 in 2015 (MacNaughton, 2016). In the last 10 years, one in every eight Canadian senior citizens (i.e., over 65 years old) is still employed compared to ten years ago, when one in 13 Canadian were employed. It

appears that over the last decade there is an increase in the number of older adults that are still active members of the workforce. Then, will there be a negative impact on those older adults if they were to retire early (i.e. before they are 65) due to chronic disease?

Early retirement is the practice of leaving one's employment before the statutory age (i.e., most often 65 years) (Canada Pension Plan, 2016). Usually, the term has positive connotations, representing a favourable financial status. However, this is not always the case for those who take early retirement due to chronic illness (Gallo, Bradley, Siegel, & Kasl, 2000). In Canada, accepting an early retirement has inherent negative financial consequences. An individual who starts receiving their Canada Pension Plan retirement pension at the age of 60 receives 36% less money than if they take it at 65 years (Canada Pension Plan, 2016). Therefore, those individuals who are required to retire before 65 may face significant financial strain if they need to rely on their pension for medical or day-to-day expenses. According to Quine, Wells, De Vaus, and Kendig (2007), the choice of retirement, rather than a requirement, helps in retirement planning and better adjustment to retired life. A mental health survey conducted on 35,015 individuals by Noorbala, Yazdi, Yasamy, and Mohammad (2004), reported that prevalence of mental disorder (e.g., depression and anxiety) was found to be greater in individuals who were retired or unemployed than those who had an employment. Although early retirement (i.e., forced early retirement due to a chronic illness) and unemployment are two different aspects, they can still have a significant negative impact on mood due to the sheer inability to have a job. Unless a person has good benefits and retirement plans, early retirement poses constraints on one's socio-economic status and

financial condition that may lead to depression (Wang et al., 2010). On the other hand,

Oksanen et al. (2011) demonstrated some benefits of early retirement on mental health

noting that the retirees used fewer antidepressants during their transition period. Some

other studies have also shown that voluntary retirement has positive effects on

individuals' physical and mental well-being, which may not be the case for involuntary

retirement (Shultz, Morton, & Weckerle, 1998). It appears that much attention was paid

to the impact of early retirement on mental health, but studies did not investigate early

retirement or forced retirement due to chronic disease as a risk factor for depression in

older adults.

According to Shih, Wu, Wakeford, and Lakdawalla (2016), the single most

common cause of forced unemployment or early retirement in PwMS is the

unpredictability of MS that affects the overall disability in these individuals. PwMS have

also reported that physical and neurological changes are other important reasons for early

retirement (Smith & Arnett, 2005). Many studies demonstrated that PwMS often seek

early retirement from their employment which leads to social isolation and decreased

overall quality of life, which may further impact their self-worth (Aronson, 1997; Kobelt

et al., 2006; Miller & Dishon, 2006; Pfleger, Flachs, & Koch-Henriksen, 2010). The

impact of early retirement and/or unemployment due to MS has not been broadly

researched, but there is some evidence that suggests a bidirectional relationship between

early retirement and depression in PwMS (Karpansalo et al., 2005; Leino-Arjas, Liira,

Mutanen, Malmivaara, & Matikainen, 1999).

Various studies on older adults encourage individuals to find age-appropriate jobs and apply for benefits for early retirement due to disability (Rice, Lang, Henley, & Melzer, 2011). This is because early retirement impacts the overall financial condition of a family as much as it affects individual's income. Two studies in the general population that used data from the Health and Retirement Survey (HRS) to examine mental health impacts of job loss among older adults reported an increase in depressive symptoms after job loss (Gallo et al., 2000; Siegel, Bradley, Gallo, & Kasl, 2003). Another cross-sectional study on 13,186 PwMS between ages 45 and 53 years, reported that approximately 33% to 45% of the sample retired early due to MS (Kobelt et al., 2006). From an economic perspective, both primary care and mental health patients show reduced productivity and more frequent use of healthcare services, which ultimately increase financial burdens of the society (Karpansalo et al., 2005).

It is difficult to compare results from different countries such as the UK, Australia, Europe and North America because the legislation surrounding pension for disability and early retirement are different in different countries. However, research worldwide has shown that MS often causes early occupational disability which forces individuals to seek early retirement from their employment (Kobelt et al., 2006; Miller & Dishon, 2006). Studies have alluded to the occupational difficulties faced by PwMS, and the ordeals of receiving an early pension (Pfleger et al., 2010). But studies have not yet considered the impact of early retirement as a potential risk factor for developing depression in PwMS. As such, clinicians should not overlook early retirement due to MS which is a potential marker for the development of depression.

The factors stated above provide a reason for the need to understand predicting factors of depression. Healthcare professionals will be able to use these variables as possible "rule outs" or "vulnerabilities" that make older adults with MS more at risk of developing depression. Policymakers can advocate for continuous supportive therapy for older people who live in one or more of these vulnerable conditions. Better awareness also increases treatment adherence in PwMS that will ultimately contribute to healthy living and healthy aging in older PwMS.

2.3 Significance of the study

Throughout the literature, researchers have explained the difficulties related to MS and the impossibility of completely curing this disease (Goodin et al., 2002). As such, it was suggested that the management of MS-related symptoms should focus on reducing physical, emotional/psychological, social and cognitive difficulties as imposed by MS. Depression is one of the most common psychological problems faced by PwMS (Andrade, 2011; Feinstein et al., 2014). Depression worsens MS symptoms, affects other comorbid diseases, slows down recovery process of MS, and interferes with an individual's motivation for treatment (Marrie & Horwitz, 2010; Marrie, Reider, et al., 2015; Marrie, Reingold, et al., 2015; Sahakyan et al., 2013; Stein-Shvachman et al., 2013). As such, the main aim of our study is to explore the independent predictors of depression in older adults with MS. Understanding the predictors of depression will help clinicians regularly screen for depression by using self-report measures and clinical interviews for those who report potential risk-factors of depression. Kennedy (2002) stated that full remission of depression is achievable through evidence-based therapy

and/or medication. However, therapy and medication for depression also add to the already existing economic burden for PwMS. Therefore, another possible reason for exploring and understanding the elements the risk factors for depression may be to screen individuals, conduct assessment, and provide treatment to those in need. This may ultimately reduce the potential worsening of MS symptoms and help lessen economic burden. The findings of this research will be able to make a significant contribution to the existing body of literature with respect to the risk-factors of depression in older PwMS.

To find the independent predictors of depression, an exhaustive literature search was done on the association of depression with various demographic and clinical variables in general population, primary care population, PwMS, and older adults. After a thorough literature search, variables were selected *apriori.* While doing the literature search, it was observed that several studies demonstrated the difficulties related to differentiating the symptoms of MS and depression due to the overlap of neurological and psychological symptoms of the two diseases (Feinstein et al., 2014; Galeazzi et al., 2005). Therefore, we decided to use two separate depression constructs that were available in the data set particularly to understand if there were any differences between depressed and non-depressed PwMS on various demographic and clinical variables when they reported being diagnosed by a medical professional and when they self-reported depressive symptoms on a depression questionnaire (HADS-D). Therefore, as a first step, we wanted to find the prevalence rate of depression as diagnosed by medical professionals. Following that we wanted to explore if there is a difference between depressed and non-depressed participants on demographic and clinical variables when participants reported

being diagnosed with depression by their medical professional. Secondly, we wanted to

find the prevalence rate of depression as when participants self-reported symptoms on the

HADS-D. Following that, we wanted to explore if there is a difference between depressed

and non-depressed participants on demographic and clinical variables when participants

self-reported symptoms on the HADS-D. After the exploration process, all those variables

that were significantly different for both medically diagnosed depression and self-

reported depressive symptoms were carried forward to the main predictive model as

potential predictors of depression.

For the predictive model, this study used a stringent technique to screen

individuals for depression. Those participants who reported being diagnosed by medical

professional as well as self-reported depressive symptoms on the HADS-D formed the

"depressed" group. The "non-depressed" group consisted to those participants who either

reported being diagnosed with depression by their medical professional, or scored above

the cut-off on the HADS-D or did not have either of the two. As discussed in the above

paragraph, the predictive variables were carried forward from the exploratory analyses as

those that had a significant association with medically diagnosed depression or self-

reported depressive symptoms.

2.4 Hypothesis

Depression is a common emotional problem in PwMS (Feinstein et al., 2014).

Depressive symptoms are sometimes difficult to identify from the symptoms of MS due

to significant neurological and psychological symptoms overlap between the two diseases

(Feinstein et al., 2014; Galeazzi et al., 2005). Exploring predictors of depression in older

PwMS will add to the preventative measures taken by PwMS, clinicians and community support workers to understand the risk-factors of depression.

Prediction: The same variables will not be significantly different in depressed and non-depressed participants when depression is assessed by a medical professional as reported by participants and when depression is assessed by a self-report questionnaire during the survey. We also hypothesize that the following personal and disease-related factors: gender, age, financial condition, early retirement due to MS, social support, number of years living with MS, physical comorbidities, physical disability and perceived disability are the independent predictors of depression in older PwMS.

Research Question 1: What is the prevalence rate of depression as diagnosed by medical professionals? Is there a difference between depressed and non-depressed PwMS on demographic and clinical variables when they reported being diagnosed with depression by their medical professional?

Research Question 2: What is the prevalence rate of depressive symptoms as measured by HADS-D during the survey? Is there a difference in PwMS between those with and without depressive symptoms on demographic and clinical variables when assessed by HADS-D?

Research question 3: What are the independent predictors of depression in older PwMS.

Chapter 3

Methods

3.1 Introduction

This cross-sectional epidemiological study employs secondary analysis of de-identified data gathered between May 2011 and December 2012 as part of the "Health, Lifestyle and Aging with MS" survey (HREB#10.06) (Ploughman, Beaulieu, & Harris, 2015). The complete methodology and initial results of the survey are already published elsewhere (Ploughman, Beaulieu, et al., 2015; Ploughman et al., 2014).

Firstly, we aim to explore the prevalence of depressive symptoms in this population through various sources (e.g., diagnosis of depression provided by a medical professional, and self-reported depressive symptoms as measured by HADS-D during the survey). We hope to gain a more vivid picture of the presentation of depression in this population both in terms of medically diagnosed depression and self-reported depressive symptoms. We also wish to explore if there were significant differences between depressed and non-depressed participants on various clinical and demographic variables. Analyses will be run separately for depressed and non-depressed group when they reported being diagnosed by a medical professional and when they self-reported depressive symptoms on the HADS-D. Finally, we wish to explore the independent predictors of depression in older PwMS. Variables were selected *apriori* after a thorough literature search on studies that identified predictors of depression in young and old PwMS, general population, and in other chronic conditions (Siracusano, Niolu, Sacchetti,

& Ribolsi, 2013). The personal factors chosen as predictors were gender, age, social

support, and financial condition and MS-related factors were number of years living with

MS, physical disability, perceived disability, early retirement due to MS, and comorbid

physical conditions.

3.2 Initial Survey Design

(Health, Lifestyle and Aging with MS survey)

The survey consisted of validated self-reported outcome tools. Additional custom-

designed questions were chosen based on pilot research in a small sample of older PwMS

(Ploughman et al., 2012). Utilizing the participant feedback that was received from the

smaller sample, a paper version of the survey was tailored to the potential needs of an

older population. The revisions to the new survey included larger font size and dividing

the survey into six sections (chapters) that grouped similar questions together: You and

Your MS (5 pages); Your Health (6 pages); Your Activities (8 pages); Your Thoughts and

Feelings (7 pages); Your Social Life (4 pages); Your Opinions (1 page) (see Appendix 4).

This was done to avoid survey fatigue, and instructions were provided for respondents

that suggested that they complete the survey in sections (i.e., chapters) taking a break in

between. In order to examine the feasibility and user-friendliness of the survey and to

minimize skipped items, the first 14 participants (11 returns) were asked to provide

feedback on the content, format, and response burden. The 11 responses were not

included in the final data, but their feedback was integrated into the final version of the

questionnaire.

The initial study was approved by 11 health research ethics boards in eight Canadian provinces: British Columbia, Alberta, Manitoba, Saskatchewan, Ontario, Quebec, Nova Scotia, and Newfoundland and Labrador. Participants in the initial study were recruited from a list generated from the MS databases in the eight provinces including sub-sites in Prince Edward Island and New Brunswick. In order to include PwMS from the province of Quebec, Canada, the entire survey including the cover letter was translated into French by one independent professional translator. French versions of previously validated tools were also obtained for those participants. Four native French speakers involved in MS research made corrections to the initial translation. The revisions were then consolidated by a fifth French-speaking MS researcher. A total number of 921 PwMS were contacted for the research study of which 743 returned the completed survey (Ploughman et al., 2012).

The complete survey consisted of a total of 147 questions all of which self-reported questions from standardized tools except for the last two questions were that were open-ended questions (see Table 1). Where needed, permission was obtained from the developers of the validated tools to use in the survey.

Table 1: *Variables and Measure of the Initial Survey (entire questionnaire)*

Chapter	Domains	Measurement Tools
1. **You and Your MS** (5pages)	**Demographics**	Postal code, gender, height, weight, age, finances and education
	MS Disease Characteristics	Symptom onset, time since diagnosis, and type of MS
	Environment	Living situation, accessibility and home modifications

	Health-Related Quality of Life	Visual analogue scale of perceived health status Multiple SclerosisImpactScale-20
2. Your Health (6pages)	**Physical Health and Disability**	Barthel Index Comorbidity Questionnaire
	HealthCare Services	Use and satisfaction with healthcare services, medications and complementary/alternative health.
3. Your Activities (7pages)	**Participation and Instrumental Activities of Daily Living**	Frenchay Activities index; Employment and impact of fatigue
	Lifestyle	Simple Lifestyle Indicator Questionnaire (diet, exercise, stress, smoking, alcohol)
4. Your Thoughts and Feelings (8pages)	**Mental/Cognitive Health**	Hospital Anxiety and Depression Scale (HADS) Resilience Scale Problems with concentration and memory
5. Your Social Life (4pages)	**Social Support**	Personal Resource Questionnaire-2000
6. Your Opinion (1 page)	**Open-ended question**	From your point of view, what are the most important things that help you live long and healthy with MS? If you would like to make any final comments about this questionnaire or the study itself, please record them in the space provided below. If you need more space for writing, feel free to attach an additional piece of paper.

3.3 Sample Population

743 Canadians of age 55 years or older with self-reported MS symptoms for 20 years or more comprised the sample of the initial study. During the data collection process in the initial survey, participants were recruited by contacting them via telephone from lists of eligible MS clinics, public advertising through the MS Society of Canada Research Internet, local MS Society chapters and their newsletters, and newspaper advertisements. A confirmed diagnosis from a neurologist was available for participants who were recruited through the MS clinic databases. Self-identified participants provided a diagnosis date and name of their neurologists to confirm their diagnosis.

3.4 Data Collection Process of the Initial Study

Ploughman and colleagues (2014) collected a large nationally representative sample, and the researchers regularly followed up at various study sites and made formal and informal contacts with MS Society Chapter support groups. Consent was obtained using a standard script, following that, the questionnaire was mailed to participants. The questionnaire package consisted of the information sheet, a toll-free telephone helpline number and email address, and a prepaid reply envelope (see Appendix 2). Participants were requested to return the completed survey within 2 weeks, and non-responders were telephoned for a reminder at 4 weeks mark. Participants were also encouraged to complete the survey by telephone who wished to do so. Each questionnaire was coded to maintain anonymity.

3.5 Present Study

This present study (i.e., the dissertation) was approved by the Health Research

Ethics Authority (HREA # 14.103), Newfoundland and Labrador to use the data for

secondary analysis. The participants' demographic composition of this present study was

the same as the initial survey conducted by Ploughman and her colleagues. 743

Canadians, 55 years or older living with self-reported MS symptoms for 20 years or more

formed the sample population of this study.

3.6 Instrument Description for the Present Study

This section described only those variables and instruments that were used in this

present study (see Table 2).

Table 2: *Variables used in the Present Study*

Variables	Measure	Survey Question	Number of Items
Demographics	Gender	2	2
	Age	3	1
	Province	1	1
	Financial Condition	12	3
	Early Retirement due to MS	80	2
MS disease	Type of MS	18	7
	Comorbidity	49	32
Affect/Mood	Hospital Anxiety and Depression Scale (Depression)- HADS-D	104, 106, 108, 110, 112,114, 116	7 (4 options in each item)
	Depression diagnosis by medical professional	49 (first column, 4th item)	1

PREDICTORS OF DEPRESSION IN MS

	Antidepressant	62	1
Disability Status	Barthel Index- BI	51-60	10
	Multiple Sclerosis Impact Scale- MSIS	19-47	29
Social Support	Personal Resource Questionnaire- PRQ	131-145	15

Demographics

Gender[1]

The gender of the participants was collected as a part of the "you and your MS" section to gather participant's demographic information. The researchers recorded the gender of the participants as male or female. Gender was coded as: 0 = "Female" and 1 = "Male" (see Appendix 1).

Age

Age was calculated by asking participants to enter their year of birth. During data entry, age was calculated by subtracting their year of birth from the year 2012. Groupings and coding for 'age' are available in (see Appendix 1).

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[1] The original survey uses the term 'gender' to differentiate between male and female respondents in terms of biological sex.

Province

Province was determined by the asking the participants to write their postal code (see Appendix 1).

Financial Condition

Financial condition was suggested through three items that asked the participants about their opinion (i.e., perception of their financial status) on whether they think they have enough, just enough, or do not have enough money to meet their daily needs so that they can live the way they want. During data entry, financial condition was coded and grouped according to participants' responses. The three groups were re-coded into two categories with "do not have enough money" classified as "0 = do not have money" and "have enough and just enough" money classified as "1 = have money" (see Appendix 1).

Primary Outcome

Depression diagnosis as provided by medical professional

Participants were presented with a list of health conditions based on a comorbidity index by Horton, Rudick, Hara-Cleaver, and Marrie (2010) and they were asked to indicate the ones that they were diagnosed with by a healthcare professional. Depression was one of the health conditions on the list. In order to categorize individuals with and without depression, the item that asked participants if they were medically diagnosed with depression was selected, and the total sample was classified into two groups (0 = no

diagnosis of depression; 1 = diagnosis of depression). Coding for this variable is available

in Appendix 1.

Self-reported depression: Hospital Anxiety and Depression Scale (HADS)

Literature highlights that symptoms of depression and anxiety are common in

PwMS and they affect a person's QoL from every aspect. There are numerous self-report

measures designed to detect mood and anxiety symptoms in the general population,

psychiatric samples as well as for patients with medical or neurological disorders.

Honarmand and Feinstein (2009) noted that many self-report measures for psychiatric

diagnosis that are administered on primary care clients do not always consider the

importance of somatic confounders like fatigue, sleep and appetite, and impaired

concentration. They explained that the somatic symptoms might be attributed to both

primary care and psychiatric conditions which may inflate the total score.

The Hospital Anxiety and Depression Scale (HADS) is a 14 item self-report

measure that detects anxiety and depression and takes somatic confounders into account

(Zigmond & Snaith, 1983). HADS is validated for the use in medical settings with PwMS

and other chronic conditions (Al-Gamal, 2015; Bratas, Gronning, & Forbord, 2014;

Honarmand & Feinstein, 2009; Paker, Bugdayci, Midik, Celik, & Kesiktas, 2013;

Rodriguez-Blazquez et al., 2009). Predetermined cut-off scores group patients into

normal (0 – 7), mild (8 – 10), moderate (11 – 14) and severe (15 – 21) ranges of

depression or anxiety separately. Scores for the entire scale (depression and anxiety)

range from 0 to 42, with higher scores indicating more distress due to depression and/or anxiety (Zigmond & Snaith, 1983).

HADS has been validated across different counties and cultures (Bocerean & Dupret, 2014; Hinz et al., 2014; Roberts, Fletcher, & Merrick, 2014) and has also been translated into various popular languages (e.g., Spanish, French) (Lane et al., 2007). In the validation study by Honarmand and Feinstein (2009), the threshold score of 8 or higher on the depression subscale provided a sensitivity of 90% and specificity of 87.3%. In this study, the seven items that assessed the presence of depression from the total 14 items on HADS was considered and was called the Hospital Anxiety and Depression Scale-Depression component (HADS-D). A score of 7 or lower on the HADS-D was considered as participates with no depressive symptoms, and a score of 8 or higher was defined as participants with depressive symptoms (Bjelland, Dahl, Haug, & Neckelmann, 2002). Presence of depression was coded as "0 = No Depressive Symptom" and "1 = Depressive Symptom" (see Appendix 1).

There are several advantages in using HADS as it works well with both medical and non-medical populations and it is a brief measure that takes no more than 5 minutes to complete (Christodoulou et al., 2010; Snaith, 2003). It requires participants to report their feelings in the past week and can be re-administered after a week's time. HADS-D formed one of the main research questionnaires for this present study that determined if participants had self-reported depressive symptoms above the cut-off point (i.e. ≥ 8).

Clinical Variables

Physical Disability: Barthel Index (BI)

Although there are various measures of disability in MS, there are no clinical

scales that are universally accepted for use in PwMS (Sharrack & Hughes, 1996). The

most widely used and popular tool for measuring disability status in PwMS has been the

Expanded Disability Status Scale (EDSS) (Kurtzke, 1983). However, one of the

limitations of the EDSS is that it is based on neurological examination and not functional

limitations and is a clinician-administered instrument. Therefore, the Barthel Index (BI)

was developed to measure the extent of someone's independent functioning and mobility

in their ADL out of the limitations posed by EDSS (Laake et al., 1995). The BI measures

activities like feeding, bathing, grooming, dressing, bowel control, bladder control,

toileting, chair transfer, ambulation and stair climbing. The index also reports the need for

assistance in PwMS. This index was initially developed for use in hospital-based

rehabilitation patients with neuromuscular difficulties and stroke (Laake et al., 1995). BI

is the most widely used assessment to measure disability in terms of difficulties with

ADL and functional limitations (Mahoney & Barthel, 1965; van der Putten, Hobart,

Freeman, & Thompson, 1999).

The BI was first developed by Mahoney and Barthel in 1965 and later modified by

Collin, Wade, Davies, and Horne in 1988 (Collin, Wade, Davies, & Horne, 1988;

Mahoney & Barthel, 1965). Formiga, Mascaro, and Pujol (2005) found a high inter-rater

reliability of the overall BI score (r =0.793) with older adults (mean age 72.6 ($\pm$11)) but

they also found that the inter-observer scores on subscales like feeding, grooming and transfers were not as high (kappa<0.4).

The original version is a 10-item instrument with the following categories: feeding, bathing, grooming, dressing, bowel control, bladder control, toileting, chair transfer, ambulation and stair climbing (Mahoney & Barthel, 1965). Items are scored as 0, 5, and 10 depending on the amount of assistance needed to do the above activities, or whether individuals can do them independently. BI is scored from $0 - 100$, with a higher score indicating greater independence. Shah, Vanclay, and Cooper (1989) suggested that scores of 0-20 indicate "total dependence", 21-60 indicate "severe dependence", 61-90 indicate "moderate dependence", 91-99 indicates "slight dependence", and 100 indicates "independence". Lewis and Shaw (2017) noted that most studies use a 60/61 cutting point. In this present study, scores on BI are used on a continuous scale with lower scores indicating more dependence.

Perceived Disability: Multiple Sclerosis Impact Scale (MSIS-29)

There are several valid and reliable measures used to assess disability status in PwMS. However, most tools assess functional ability and limitations in PwMS to be able to understand the progression of MS (Giordano et al., 2009). These popular clinical tools are nonetheless unable to holistically evaluate the effects of MS on an individual's physical and psychological functioning. MSIS-29 is a 29-item condition-specific, self-report questionnaire that is geared towards measuring the individual's view on the impact

of MS on their HRQoL, their everyday functioning, and their perceived levels of disability posed by MS (Giordano et al., 2009).

MSIS-29 is divided into two subscales: a 20-item physical impact scale and a 9-item psychological impact scale. Scores on the physical impact scale can range from 20 to 80 and on the psychological impact scale from 9 to 36. Lower scores on the MSIS-29 indicate less impact of MS, while higher scores indicate a more significant effect of MS (Riazi, Hobart, Lamping, Fitzpatrick, & Thompson, 2002). The validity, reliability and consistency of the psychometric properties of the MSIS-29 have been established in different settings by various researchers (Riazi et al., 2002). The MSIS-29 was created based on qualitative interviews with PwMS following a thorough evaluation and employed both traditional and modern psychometric approaches (Hawton, Green, Telford, Zajicek, & Wright, 2012; Hobart & Cano, 2009; McGuigan & Hutchinson, 2004).

Social Support: Personal Resource Questionnaire (PRQ)

The PRQ scale is used to measure the participants' social support. The PRQ consists of 15 short statements on a seven-point Likert scale (from 1-Strongly Disagree to 7-Strongly Agree). The participants report the degree to which they agree or disagree with each statement. Higher scores on the PRQ indicate higher levels of social support (Weinert and Brandt, 1987). According to Weinert and Brandt (1987), the formation of the PRQ was based on five underlying concepts: one is valued (worth), one is an integral part of a group (social integration), the provision for attachment/intimacy (intimacy),

opportunity for nurturance (nurturance), and availability of informational, emotional and

material help. The PRQ demonstrates good content, predictive and construct validity

(Brandt & Weinert, 1981; Weinert, 1984). In a systematic review, Tawalbeh and Ahmad

(2013) reviewed nine studies that used PRQ and reported that the internal consistency

raged between 0.87 to 0.93 and provided positive evidence for construct validity when the

PRQ was used in relation with various study variables including disability, loneliness,

depression, stress, pain and so on. The researchers also noted the diverse demographic

composition in terms of age, socioeconomic status, ethnicity and educational level that

were used in the different studies. Fong, Finlayson, and Peacock (2006) reported the use

of PRQ to measure social support in PwMS.

Early Retirement due to MS

This is a single item that was extracted from the tool called the Frenchay

Activities Index (FAI) that inquired about an individual's level of participation in

productive work and instrumental activities of daily living, and their employment status

(Nouri & Lincoln, 1987). The statement asked participants to answer in "yes" or "no" if

they had to retire early or had to stop working because of MS. Early retirement due to MS

was coded as 0 = no and 1 = yes (see Appendix 1).

Type of MS

According to the National MS Society (2015), there are four main types of MS

(Primary-Progressive, Secondary-Progressive, Relapsing-Remitting and Progressive-

Relapsing) and they have been categorized by the symptom manifestations. The two most

common types of MS are the relapsing-remitting followed by the primary-progressive type (Hooper 2011; & Tremlett, Yousefi, Devonshire, Rieckmann, & Zhao, 2009). As such, only these two types were considered in the analysis (see Appendix 1).

Number of years living with MS diagnosis

Participants were asked to indicate the year when they were officially diagnosed with MS by a healthcare professional. During data entry, time since MS diagnosis was calculated by subtracting their reported year of official MS diagnosis from the year 2012. Groupings and coding for this variable is available in (see Appendix 1).

Physical Comorbidities

Participants were provided with a list of possible comorbid conditions that were determined through Marrie and Horwitz's Comorbidity Questionnaire (Marrie & Horwitz, 2010). Conditions such as anxiety disorder, bipolar disorder and depression did not form a part of this variable. All the other conditions were considered.

Antidepressant

Antidepressants are psychiatric medications that are given to people with mood disorders to alleviate their symptoms. However, it must be noted that antidepressants may also be used for other psychiatric conditions besides depression, for example, anxiety disorders. At the same time, some other psychotropic medications like antiepileptic drugs that were prescribed to PwMS in this population may also alleviate mood-related symptoms. Participants were asked to provide names of all the drugs that they were currently taking for MS and other health conditions. Antidepressants were noted, and the

number of participants taking antidepressants was counted in order to know the sample size of people who were diagnosed with depression and had been taking medication for depression.

3.7 Data Analysis

Data analyses were performed using IBM SPSS (Statistical Package for the Social Sciences) V. 21 software. As a first step, test for normality was run. Then, descriptive statistics were used to explore demographic and clinical characteristics of the population in terms of depression diagnosed by a healthcare professional (i.e., medically diagnosed depression), and self-identified depressive symptoms as measured by HADS-D.

Individuals with and without a diagnosis of depression, and self-reported depressive symptoms were compared based on various demographic and MS-related variables. Based on previous research a list of 'a priori' factors that are potentially associated with depression in older PwMS was categorized into two domains; (1) demographic, and (2) clinical. Demographic information included age, gender, years of education, social support (PRQ), current financial condition, province of individual, living situation, current employment status, and early retirement due to MS. Clinical factors included type of MS, number of years living with MS, self-reported depression, using antidepressant, physical comorbidities, physical disability (BI), and perceived disability (MSIS).

From the above-mentioned factors, the continuous variables were analyzed using independent samples t-tests, and the categorical variables were analyzed using chi-square tests.

An alpha level of .05 was used for determining significance. The alpha level of .05 was set based on the following explanation provided by Cramer and Howitt (2004),

"The level at which the null hypothesis is rejected is usually set as 5 or fewer times out of 100. This means that such a difference or relationship is likely to occur by chance 5 or fewer times out of 100. This level is generally described as the proportion 0.05 and sometimes as the percentage 5%. The 0.05 probability level was historically an arbitrary choice but has been accepted as a reasonable choice in most circumstances. If there is a reason to vary this level, it is acceptable to do so. So, in circumstances where there might be very serious adverse consequences if the wrong decision were made about the hypothesis, then the significance level could be made more stringent at, say, 1%" (p. 151).

Various studies discussed the difficulties related to diagnosing depression due to overlapping of symptoms with MS when a self-reported measure is used to assess depression (Feinstein et al., 2014; Gunzler et al., 2015). For this reason, we wanted to examine if there was a difference between depressed and non-depressed PwMS in terms of demographic and clinical variables when their depression is diagnosed by a medical professional versus when depression is assessed by self-reported questionnaire. For the first instance, depression, as diagnosed by a medical professional, the item on the comorbid disease list that enquired about a participant's diagnosis of depression was used

to create the first outcome measure (i.e., medically diagnosed depression). We classified

respondents into 'No Diagnosis of Depression' or 'Diagnosis of Depression.' The first

research question explored differences in the demographic and clinical factors between

those who were medically diagnosed with depression and those who were not. For the

second outcome measure, self-reported depressive symptoms as measured by HADS-D

cut-off score ($\geq$8) was used, and the total sample was classified as 'No Depressive

Symptoms' or 'Depressive Symptoms.' Individuals whose scores were 7 and below were

considered sample without self-reported depressive symptoms and individuals whose

score were 8 and above, were considered sample with self-reported depressive symptoms.

The second research question explored differences in the demographic and clinical factors

between those who met the cut-off criteria on the HADS-D and those that did not.

Independent samples t-tests were run to analyze if there is a significant difference

between depressed and non-depressed PwMS when the were diagnosed with depression

by a medical professional with respect to the following variables: age, total years of

education, total number of physical comorbidities, number of years living with MS, social

support, physical disability, and perceived disability. Separate independent samples t-tests

were run with the same independent variables in order to analyze if there is a significant

difference between individuals who self-reported depressive symptoms and those who did

not. All t-tests were also subjected to Levene's Test of Equality of Variances. The

variables that were statistically significant on the Levene's Test for Equality of Variances

indicated that group variances were unequal. As such, in order to correct the violation,

non-pooled variances and Welch-Satterthwaite adjusted degrees of freedom were used for comparison purposes.

A chi-square test was run to analyze if there is a significant difference between participants who reported being diagnosed with depression by their medical professional versus those who did not. The categorical variables selected apriori are: gender, living situation, current financial condition, type of MS, total years of education, use of antidepressant, employment status, early retirement due to MS, and province of individuals. A separate chi-square test was run with the same categorical variables in order to analyze if there is a significant difference between individuals who self-reported depressive symptoms and those who did not. Odds ratio was calculated for those variables had a significant relationship with medically diagnosed depression and/or self-identified depressive symptoms.

A Pearson's Correlation analysis was done to explore the significant relationships between depression (i.e., self-reported depressive symptoms and medically diagnosed depression) and the study variables (i.e., age, gender, early retirement due to MS, financial condition, number of years living with MS, physical comorbidity, social support, perceived disability and physical disability) in older PwMS.

A Bonferroni correction was not conducted for the initial two t-tests as they were entirely performed as an exploratory method to find the demographic and clinical variables (on a continuous scale) that were in someway significantly different in depressed and non-depressed participants. The significant variables were then carried forward to the confirmative predictive model. A stringent correction in the first step may

not have helped in including all possible variables for the confirmative predictive

analyses as the variables would have deviated further away from the 0.05 level.

Moreover, it would have increased false negatives (type II error rate) (Cohen, 1994).

The clinical and demographic variables were selected *apriori* after an exhaustive

literature search in terms of association of the above variables with depression in the

general population, primary care population, in PwMS, and in older adults. The t-tests

and chi-square tests were used to explore those significant variables connected to self-

reported depressive symptoms and medically diagnosed depression. Following the t-tests

and chi-square analyses, all those demographic and clinical variables that had a

statistically significant or trending relationship with depression (as determined by p-

values < .05) (i.e., depression diagnosed by medical professional or HADS-D) were then

carried forwards to examine the independent predictors of depression in older PwMS.

Given the difference between the two ways of defining depression (i.e., medically

diagnosed depression and self-reported depressive symptoms), information from both

classifications is used to define 'Depression' in the final analysis. To create the final

outcome for the predictive model, those participants who reported that they had been

diagnosed with depression by their medical professional as well as self-identified as

having depressive symptoms were classified as 'Depressed' and those who did not have a

depression diagnosis or did not self-identify depressive symptoms were classified as

'Non-depressed.' This means that only those participants who had a diagnosis of

depression as well as scored ≥8 on HADS-D formed the sample for the final analysis. The

resulting classification provides for a clearer distinction between those who are or are not

depressed. 'Non-depressed' participants were coded as 0, and 'Depressed' participants were coded as 1. Since the dependent variable is binary in nature, a logistic regression model was used to estimate the risk factors for depression.

Chapter 4

Results

4.1 Overall Demographic and Background Characteristics

Of 743 potential participants, 577 were women and 166 were men, and they were

between the ages of 55 and 88 years.

4.2 Research Questions

Research Question 1: What is the prevalence rate of depression as diagnosed by

medical professionals? Is there a difference between participants who reported versus

who did not report being diagnosed with depression by their medical professional in

terms of demographic and clinical variables?

A chi-square analysis showed that 191 (25.7%) participants reported receiving a

diagnosis of depression from their medical professional.

Upon conducting the independent sample t-test, the Levene's Test for Equality of

Variances was statistically significant, for perceived disability, and number of physical

comorbidities indicating that the group variances were unequal in this population.

Therefore, the t-tests for these comparisons used non-pooled variances and Welch-

Satterthwaite adjusted degrees of freedom (see Table 3). The analysis showed that

participants who did and did not report receiving a diagnosis of depression from their

medical professional did not differ on some demographic and clinical variables such as

age, $t(741) = 1.39$, $p = .164$, Cohen's $d = 0.1$; total years of education, $t(741) = -1.08$, $p = $

.281, Cohen's $d = 0.08$; physical disability, $t(741) = 1.13$, $p = .259$, Cohen's $d = 0.08$; and

number of years living with MS, $t(741) = 1.10$, $p = .273$, Cohen's $d = 0.08$. It was

however also noted that participants who did and did not report receiving a depression

diagnosis from their medical professional differed on many clinical and demographic

variables such as total number of physical comorbidities, $t(305.37) = -4.74$, $p < .0005$,

Cohen's $d = -0.54$; social support, $t(739) = 3.12$, $p = .002$, Cohen's $d = 0.23$; and

perceived disability, $t(295.67) = -4.12$, $p < .0005$, Cohen's $d = -0.78$. Therefore,

individuals who were diagnosed with depression by their medical professional had more

comorbid physical conditions, than those who did not have a diagnosis of depression.

Participants self-reporting a depression diagnosis by their medical professional also had

significantly lower social support than those who did not. Lastly, participants self-

reporting a diagnosis of depression by their medical professional perceived themselves as

significantly more disabled than those who did not.

Table 3: *Descriptive Statistics: Demographics and clinical profile of depressed and non-depressed participants according to the diagnosis provided by the medical professionals (N = 743)*

Demographics & Clinical Profile	*Total Population*		*No Diagnosis of Depression* N = 552 (74.3%)	*Diagnosis of Depression* N = 191 (25.7%)	*p*
	Mean (SD)	Range	Mean (SD)	Mean(SD)	
Age	64.62 (6.18)	55-88	64.81 (6.17)	64.08 (6.18)	
Total years of education	13.47 (2.55)	5-25	13.41 (2.52)	13.64 (2.66)	
Number of years living with MS	24.82 (10.02)	0-66	25.05 (10.06)	24.13 (9.89)	
Total number of Physical Comorbidities	2.15 (1.87)	0-12	1.95 (1.79)	2.72 (1.97)	***

Social Support (PRQ)	83.45 (16.87)	16-105	84.58 (16.48)	80.19 (17.6)	**
Physical Disability (BI)	76.17 (24.78)	0-100	76.78 (24.66)	74.42 (25.10)	
Perceived Disability (MSIS)	77.96 (25.64)	29-140	75.7 (24.39)	84.48 (28.02)	***

*$p< .05$. **$p< .01$. ***$p < .001$.

Perceived Disability measured by MSIS- Multiple Sclerosis Impact Scale;
Physical Disability measured by BI- Barthel Index;
Social Support measured by PRQ- Personal Resource Questionnaire,
Diagnosis of Depression as assessed by participants' medical professional.

A chi-square test of independence was used to determine if there was a significant relationship between individuals with and without a depression diagnosis on various demographic and clinical categorical variables. A significant effect was found between gender and depression, $x^2(1) = 4.63$, $p = .019$; between early retirement due to MS and depression, $x^2(1) = 12.15$, $p = .007$; and between self-reported depressive symptoms and depression diagnosed by a medical professional, $x^2(1) = 26.94$, $p < .0005$.

The chi-square analysis also showed that the percentage of participants who reported were diagnosed with depression by their healthcare professional did not differ by RRMS type, $x^2(1) = 3.28$, $p = .070$; or by PPMS type, $x^2(1) = 2.54$, $p = .111$. The percentage of participants self-reporting depression by their medical professional did not differ depending on type of home participants lived in and depression, $x^2(2) = 0.018$, $p = .991$; use of antidepressant and depression, $x^2(1) = 0.04$, $p = .510$; between current financial condition and depression, $x^2(1) = 1.77$, $p = .110$; by province of the participant and depression, $x^2(10) = 17.46$, $p = .065$; and current employment status and depression, $x^2(4) = 5.68$, $p = .224$ (see Table 4). In terms of the odds ratio, it was found that the odds

were 0.63 times higher for a male participant to be diagnosed with depression than a

female participant. Similarly, the odds were 4.62 times higher for a person who had to

retire early due to MS to be diagnosed with depression than a person who did not have to

retire early due to MS. Lastly, the odds ratio were 2.45 times higher for participants who

reported receiving a depression diagnosis by their medical professional to also have

higher than cut-off score on depression questionnaire as during the time of the survey.

Table 4: *Descriptive Statistics: Demographics, Disease Characteristics and Financial Characteristics of depressed and non-depressed participants according to the diagnosis provided by their medical professional (N = 743)*

Demographics, Disease & Financial characteristics	Total Population		No Diagnosis of Depression N = 552 (74.3%)	Diagnosis of Depression N = 191 (25.7%)	
	N	%	N (%)	N (%)	*p*
Gender					
Male	166	22.3	134 (24.3)	32 (16.8)	*
Female	577	77.7	418 (75.7)	159 (83.2)	
Relapsing-Remitting MS					
No	357	48	276 (50)	81 (42.4)	
Yes	386	52	276 (50)	110 (57.6)	
Primary-Progressive MS					
No	644	86.7	472 (85.5)	172 (90.1)	
Yes	99	13.3	80 (14.5)	19 (9.9)	
Self-Reported Depression					
No	514	69.4	410 (74.5)	104 (54.5)	***
Yes	227	29.6	140 (25.5)	87 (45.5)	
Antidepressant					
Not Taking	706	95	524 (94.9)	182 (95.3)	

One or more	37	5	28 (5.1)	9 (4.72)	
Living Situation					
House	716	96.4	532 (96.4)	184 (96.3)	
Assisted Living Complex	16	2.2	12 (2.2)	4 (2.1)	
Long-term care facility	11	1.5	8 (1.4)	3 (1.6)	
Current Employment Status					
Unemployed	166	22.3	122 (22.1)	44 (23)	
Employed (Casual)	24	3.2	15 (2.7)	9 (4.7)	
Employed (part-time)	19	2.6	14 (2.5)	5 (2.6)	
Employed (full-time)	30	4	27 (4.9)	3 (1.6)	
Retired	504	67.8	374 (67.8)	130 (68.1)	
Early Retirement due to MS					
Yes	560	75.5	403 (73.1)	157 (82.2)	**
No	182	24.5	148 (26.9)	34 (17.8)	
Current Financial Condition					
Have Money	578	77.8	436 (79)	142 (74.3)	
Do not have Money	165	22.2	116 (21)	49 (15.7)	
Province					
NL	48	6.5	36 (6.5)	12 (6.3)	
PEI	6	0.8	4 (0.7)	2 (1)	
NB	14	1.9	10 (1.8)	4 (2.1)	
NS	123	16.6	97 (17.6)	26 (13.6)	
QC	78	10.5	66 (6.3)	12 (10.5)	
ON	105	14.1	82 (14.9)	23 (12)	
MB	70	9.4	53 (9.6)	17 (8.9)	
SK	61	8.2	47 (8.5)	14 (7.3)	
AB	80	10.8	49 (8.9)	31 (16.2)	
BC	156	21	107 (19.4)	49 (25.7)	

| | YK | 2 | 0.3 | 1 (0.2) | 1 (0.5) |

*p< .05. **p< .01. ***p < .001.

Out of the 743 individuals who participated in the study, 552 (74.3%) of them were not diagnosed with depression by their medical professional and 191 (25.7%) individuals were diagnosed with depression (see Table 4).

Four hundred and ten out of 552 non-depressed participants did not self-report symptoms of depression over the past two weeks during the time of the survey. One hundred and four participants out of the 191 participants who reported receiving a depression diagnosis by their medical professional, also self-reported depressive symptoms during the time of this survey. Two hundred and twenty-seven participants self-reported depressive symptoms on the depression questionnaire during the survey, but only 191 individuals reported receiving a depression diagnosis by their medical professional. Therefore, 36 PwMS who reported depressive symptoms on the depression questionnaire did not report being diagnosed with depression by their medical professional (see Table 4).

During the survey, a total of 504 individuals with and without depression diagnosis reported as being retired. However, 560 individuals with and without depression diagnosis reported having to retire early due to their MS. It must be noted that the number of individuals retiring is different because early *retirement due to MS* specifically required participants to answer if they had to leave their job or give up their work as a result of health adversities due to MS. However, it may be possible that whenever their health adversities were tackled, individuals were able to return to their

previous job or started a new job. As such, when participants were asked about their *current employment status*, many individuals reported being retired which may not be because of MS. from the analysis it was found that there was a significant difference between individuals with and without depression in terms of early retirement due to MS (see Table 4).

On a side note, from the data that was collected, it was observed that the timeline of individuals' reported diagnosis of depression by their medical professional was significantly widespread. The average number of years participants living with a depression diagnosis was found to be 17.54, with the maximum being 67 years ago and minimum being 1 year ago from the time when the participants completed this survey in 2012. Out of 191 individuals who reported being diagnosed with depression by their medical professional, 132 (69.1%) individuals were able to provide an approximate year of their depression diagnosis.

Research Question 2: What is the prevalence rate of depressive symptoms as measured by HADS-D during the survey? Is there a difference between participants with and without depressive symptoms on demographic and clinical variables when assessed by HADS-D?

Upon conducting the independent-samples t-test, the Levene's Test for Equality of Variances was statistically significant, for physical disability, and social support. Therefore, in order to correct this violation, the t-tests for these comparisons used non-pooled variances and Welch-Satterthwaite adjusted degrees of freedom (see Table 5).

Through the t-test analysis, it was found that participants with and without self-reported depressive symptoms did not differ on various demographic or clinical variables such as total years of education, $t(739) = -1.328$, $p = 0.188$, Cohen's $d = -0.097$; number of years living with MS, $t(739) = 0.36$, $p = 0.72$, Cohen's $d = 0.026$; and total number of physical comorbidities, $t(739) = 1.34$, $p = 0.182$, Cohen's $d = 0.098$.

It was noted that individuals with and without depression did differ on a number of clinical and demographic variables such as age, $t(739) = 3.15$, $p = 0.002$, Cohen's $d = 0.232$, physical disability, $t(370.64) = 5.16$, $p < 0.0001$, Cohen's $d = 0.56$, and social support, $t(371.94) = 11.31$, $p < 0.0001$, Cohen's $d = 1.17$, and perceived disability, $t(739) = -12.19$, $p < 0.0001$, Cohen's $d = -0.896$. Therefore, participants who are younger in age self-reported depressive symptoms more than those who were older; those individuals who self-reported depressive symptoms were also noted to have more significant physical disabilities that those who did not self-report depressive symptoms. In terms of social support, participants who did not self-report depressive symptoms had significantly more social support than those who self-reported depressive symptoms. Lastly, those who self-reported depressive symptoms had significantly greater levels of perceived disability than those who did not self-report depressive symptoms on the HADS-D.

Table 5: *Descriptive Statistics: Demographics, clinical profile and psychological factors of self-reported depressed and non-depressed participants (N = 743)*

Demographics& Clinical Profile	Total Population		No Depressive Symptoms (HADS-D) N = 514 (69.1%)	Depressive Symptoms (HADS-D) N = 227 (30.5%)	
	Mean (SD)	Range	Mean (SD)	Mean(SD)	p
Age	64.62 (6.18)	55-88	65.08(6.32)	63.54(5.70)	**
Total years of education	13.47 (2.55)	5-25	13.55(2.45)	13.29(2.77)	
Number of Years living with MS	24.82 (10.02)	0-66	24.92(10.24)	24.63(9.54)	
Total number of Physical Comorbidities	2.15 (1.87)	0-12	2.08(1.91)	2.01(1.77)	
Social Support (PRQ)	83.45 (16.87)	16-105	87.96(14.55)	73.08(17.26)	***
Physical Disability (BI)	76.17 (24.78)	0-100	79.44(22.84)	68.72(27.39)	***
Perceived Disability (MSIS)	77.96 (5.64)	29-140	70.96(23.57)	93.69(23.01)	***

*p< .05. **p< .01. ***p < .001.

Perceived Disability measured by MSIS- Multiple Sclerosis Impact Scale;
Physical Disability measured by BI- Barthel Index;
Social Support measured by PRQ- Personal Resource Questionnaire,
Depressive Symptoms measured by HADS-D- Hospital Anxiety and Depression Scale (Depression)

A chi-square test of independence was calculated comparing self-reported depression and various demographic and clinical variables that are categorical in nature. A significant interaction was found between gender and depression, $x^2(1) = 6.31$, $p = 0.008$. A significant interaction was found between early retirement of individuals due to MS and depression, $x^2(1) = 12.15$, $p < .0005$, where depressed individuals were more likely to take early retirement. A significant interaction was also found between

individual's financial condition and depression, $x^2(1) = 28.4$, $p < .0001$, where depressed individuals were more likely to say that they did not have enough money.

The percentage of participants that were depressed did not differ in terms of RRMS type, $x^2(1) = 1.605$, $p = .21$; or PPMS $x^2(2) = 1.198$, $p = .27$; by living situation, $x^2(2) = 0.005$, $p = 0.99$; by antidepressant consumption, $x^2(1) = 0.015$, $p = .90$; MS type, $x^2(6) = 5.23$, $p = .52$; and employment status, $x^2(4) = 6.69$, $p = 0.15$ (see Table 4).

In terms of the odds ratio, it was found that the odds were 1.58 times higher that a male individual will report depressive symptoms compared to a female individual. Similarly, the odds were 2.02 times higher that a person who had to retire early due to his/her MS would be more likely to report depressive symptoms compared to a person who did not retire early, and lastly, the odds were 2.6 times higher for a person who perceived as not having enough money to report depressive symptoms than a person who perceives as having enough money.

Out of the 743 individuals who participated in the study, 514 (69.1%) did not self-report depressive symptoms (HADS-D score < 8). Two hundred and twenty-nine individuals (30.8%) reported self-identified symptoms of depression (HADS-D score ≥ 8) (see Table 6).

On a final note regarding physical comorbidities, those PwMS who were medically diagnosed with depression had a significant association with hypercholesterolemia, arthritis, and irritable bowel syndrome. Participants' self-identified depressive symptoms were found to have significant associated with lung disease. Only

arthritis was found to have a significant association with depression in older PwMS who

self-reported depressive symptoms and were medically diagnosed with depression.

Table 6: *Descriptive Statistics: Demographics, Disease Characteristics and Financial Characteristics of self-reported depressed and non-depressed PwMS (N= 743)*

Demographics, Disease & Financial characteristics	Total Population		No Depressive Symptoms N = 514 (69.1%)	Depressive Symptoms N = 227 (30.5%)	
	N	%	N (%)	N (%)	*p*
Gender					
Male	166	22.4	102 (19.8)	64 (28.2)	*
Female	575	77.6	412 (80.2)	163 (71.8)	
Relapsing-Remitting					
No	356	48	229 (46.5)	117 (51.5)	
Yes	385	52	275 (53.5)	110 (48.5)	
Primary-Progressive					
No	642	88.6	450 (87.5)	192 (84.6)	
Yes	99	13.4	64 (12.5)	35 (15.5)	
Antidepressant					
None	704	95	488 (94.9)	216 (95.2)	
1 or more	37	5	26 (5.1)	11 (4.8)	
Living Situation					
House	715	96.5	496 (96.85)	219 (96.5)	
Assisted Living Complex	16	2.0	11 (2.1)	5 (2.2)	
Long-term care facility	10	1.3	7 (1.4)	3 (1.3)	
Employment Status					
Unemployed	165	22.3	106 (20.6)	59 (26.0)	
Employed (Casual)	24	3.2	19 (3.7)	5 (2.2)	
Employed (part-time)	19	2.6	15 (2.9)	4 (1.8)	
Employed (full-time)	30	4	25 (4.9)	5 (2.2)	
Retired	503	67.9	394 (67.9)	154 (67.8)	
Early retirement due to MS					
Yes	558	75.4	368 (71.7)	190 (83.7)	***
No	190	25.6	145 (28.3)	37 (16.3)	

Current Financial
Condition

Have money	577	77.9	428 (83.3)	149 (65.6)	***
Do not have money	164	22.1	86 (16.7)	78 (34.4)	

Province

NL	48	6.5	35 (6.8)	13 (5.7)	
PEI	6	0.8	5 (1)	1 (0.4)	
NB	14	1.9	12 (2.3)	2 (0.9)	
NS	123	16.6	84 (16.3)	39 (17.2)	
QC	78	10.5	49 (9.5)	28 (12.3)	
ON	105	14.1	70 (13.6)	35 (15.4)	
MB	70	9.4	50 (9.7)	19 (8.4)	
SK	61	8.2	39 (7.6)	22 (9.7)	
AB	80	10.8	54 (10.5)	26 (11.5)	
BC	156	21	114 (22.2)	42 (18.5)	
YK	2	0.3	2 (0.4)	0 (0)	

*$p< .05$. **$p< .01$. ***$p < .001$.

Table 7: *Pearson's Correlation Analysis of Study Variables to Explore the Significant Association with Self-Reported Depressive Symptoms and Medically Diagnosed Depression in Older PwMS.*

Variables	1	2	3	4	5	6	7	8	9	10	11
1. Gender	-										
2. Age	.069	-									
3. Early retirement due to MS	.041	-.128**	-								
4. Financial condition	.007	.107**	-.162**	-							
5. Number of years living with MS	.015	.263**	.061	.051	-						
6. Number of physical comorbidities	-.076*	.292**	.005	-.055	.077*	-					
7. Perceived disability	.050	-.012	.330**	-.299**	.048	.062	-				
8. Physical disability	-.035	-.089*	-.221**	.142**	-.202**	.031	-.573**	-			
9. Social support	-.046	.117**	-.089*	.218**	-.001	.009	-.236**	.088*	-		
10. Self-reported depressive symptoms	.092*	-.115**	.128**	-.196**	-.013	-.049	.409**	-.199**	-.406**	-	
11. Medically diagnosed depression	.046	-.051	.052	-.108**	.032	.082*	.264**	-.130**	-.239**	.549**	-

Note.
*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).
***. Correlation is significant at the 0.001 level (2-tailed).
MSIS- Multiple Sclerosis Impact Scale; BI- Barthel Index; PRQ- Personal Resource Questionnaire
HADS-D- Hospital Anxiety and Depression Scale (Depression)

4.3 Predictors of Depression

Research question 3: What are the independent predictors of depression in older PwMS?

The goal of this research question was to explore which demographic and clinical variables independently predicted depression in older PwMS after taking into account the other variables. To have a more parsimonious model, the predictors included only those variables that had a significant relationship with either medically diagnosed depression or self-identified depressive symptoms. Table 7 lists these predictors and provides the intercorrelations between these predictors. As can be seen from this table, the intercorrelations are not excessively high, so there are no concerns of multicollinearity. Age, gender, early retirement due to MS, current financial condition, physical comorbidities, perceived disability, physical disability, and social support are the seven predicting variables. A conservative method was used to construct the dependent variable (presence and absence of depression) for the final predictive model. Depressed participants are classified as those who self-reported depressive symptoms on HADS-D and reported being diagnosed with depression by their medical professional. Non-depressed participants on the other hand, are classified as those who either had medically diagnosed depression but had a score lower than the cut-off on the HADS-D, or vice versa, or neither (i.e., lower than cut-off on HADS-D or no depression diagnosis by a medical professional).

The results from the previous two research questions demonstrated that each way of defining depression leads to different patterns of results, which offers support to the

finding that it is difficult to diagnose depression in people with MS (Gunzler et al., 2015; Tylee & Gandhi, 2005; Feinstein et al., 2014). One hundred and four people were diagnosed with depression but did not meet the HADS-D cut-off score and 140 people scored above the HADS-D cut-off but were not diagnosed with depression. They were classified as non-depressed participants along with those who did not self-report depressive symptoms and reported not receiving a depression diagnosis. For the final analysis, it was found that 656 (88.3%) participants were 'Non-depressed' and 87 (11.7%) participants were 'Depressed.'

The Omnibus Tests of Model Coefficients table indicated that the inclusion of the predictive variables contributed significantly to model fit. The p value was less than .05 ($p < .0001$) which meant that there was some predictive capacity in the regression equation and that the block 1 model was a significant improvement to the block 0 model.

The analysis revealed that the significant predictors which had a unique contribution in predicting depression were social support, perceived disability, and physical comorbidity when all other independent variables were controlled. It was found that the odds of having depression were greater for people with less social support. For every 1 unit decrease in the score on the social support measure (i.e., PRQ), the odds of a participant being depressed increased by a factor of 0.97 (Odds Ratio [OR] = .97; 95% CI [0.96, 0.98]; p < .0001). In other words, with every unit decrease in the score on PRQ, the odds of a participant having depression increased by 3.2%. The odds of having depression were greater for participants with higher levels of perceived disability. For every 1 unit increase in the score on the perceived disability measure (i.e., MSIS), the odds of a

participant being depressed increased by a factor of 1.03 (OR = 1.03; 95% CI [1.02, 1.05]; $p < .0001$). In other words, with an additional increase in the score on MSIS, the odds of a participant having depression increased by 3.34%. The odds of having depression was greater for people with increasing number of comorbid physical conditions (OR = 1.17; 95% CI [1.03, 1.33]; $p = .015$). It was found that for an additional comorbid physical condition, the odds of having depression increased by 17.2%.

From the multivariate analysis it was found that age, gender, early retirement due to MS, current financial condition, and physical disability were not significant predictors of depression in older PwMS (see Table 8). However, when medically diagnosed depression and self-identified depressive scores were considered separately, the above variables were shown to have a significant association with either or both forms of depression.

Table 8: *Summary of Multiple Logistic Regression Analysis of the Significant Variables to Determine the Predictors Depression in Older PwMS.*

		Predictors of Depression		
Predictors	B	e^B (Odds Ratio)	95% C.I.	*p*
Age	-0.033	0.968	[0.93, 1.01]	.143
Gender	0.368	1.445	[0.83, 2.51]	.191
Early Retirement due to MS	-0.375	0.687	[0.36, 1.31]	.257
Current Financial Condition	0.060	1.061	[0.61, 1.84]	.831
Physical Comorbidities	0.159	1.172	[1.03, 1.33]	.015*
Perceived Disability	0.033	1.034	[1.02, 1.05]	<.0001***
Physical Disability	0.001	1.001	[0.99, 1.01]	.709
Social Support	-0.032	0.968	[0.96, .98]	<.0001***

Note:e^B = exponentiated *B*(Odds Ratio). Independent Variables (gender, age, current financial condition, early retirement due to MS, total physical comorbidity, perceived disability, physical disability, and support).
*p< .05. **p< .01. ***p < .001.*
Perceived Disability measured by MSIS- Multiple Sclerosis Impact Scale;
Physical Disability measured by BI- Barthel Index;
Social Support measured by PRQ- Personal Resource Questionnaire,
Depressive Symptoms measured by HADS-D- Hospital Anxiety and Depression Scale (Depression)

Chapter 5

Discussion

5.1 Findings

This chapter is divided into six sections. In the first part, there will be an overall

review of the prevalence of depression in older PwMS that formed the cohort. Several

studies have demonstrated the difficulty in isolating depressive symptoms from MS-

related symptoms due to the frequently occurring overlap in MS and depression (e.g.,

sleep difficulties, appetite, fatigue, cognitive functioning) (Gunzler et al., 2015; Tylee &

Gandhi, 2005). As such, this study attempted to explore if there is a difference in

depressed and non-depressed participants on two aspects (i.e., when participants reported

receiving a diagnosis of depression by their medical professional and when participants

self-reported depressive symptoms as assessed by HADS-D) in terms of demographic and

clinical variables. In order to find the independent predictors of depression in PwMS, this

study employed a more stringent method of selection criteria (i.e., depressed and non-

depressed). Individuals who reported receiving a diagnosis of depression from a medical

professional, as well as self-identified depressive symptoms formed the part of the

depressed group. Following the review of the prevalence of depression in PwMS, each

research question will be presented with their results, and they will be discussed with

references from the literature. Reasons behind possible variations from the literature

compared to this present study, will also be addressed. Next, the general implications of

this study will be offered. The need for continuous monitoring of depressive symptoms

and the role of multidisciplinary teams to provide holistic care to older PwMS will be

discussed as a possible way to tackle depression in this population. The strengths and

challenges of this study will be presented, followed by suggestions for future research.

Finally, a general conclusion will be presented at the end of this chapter.

5.1a. Prevalence of Depression

This study supports the claim that depression is a common psychological disorder

in older PwMS, as was shown by previous research (Feinstein & Feinstein, 2001; Katon,

2011; Mrabet et al., 2014; Patten et al., 2000). In our study, the life time prevalence rate

of depression when participants reported being diagnosed by their medical professional is

25.7%. The prevalence rate of depression when participants self-reported depressive

symptoms during the time of the survey through a depression questionnaire (HADS-D)

30.5%. Both these rates of depression are very close to each other as well as a robust

systematic review of 118 research studies, that reported the prevalence rate of depression

in PwMS to be approximately 23.7% (95% CI: 17.4%-30.0%) (Marrie, Reingold, et al.,

2015). Patten, Beck, Williams, Barbui, & Metz (2003) conducted a study using data from

the CCHS and did brief interviews on PwMS (age 18 to 45years). Patten and colleagues

reported a 25.7% prevalence rate of major depression in their population which is also

similar to the prevalence rate of our study among the participants who reported receiving

a depression diagnosis by their medical professional (i.e., 25.7%). Those research studies

that used a cut-off score on a self-report measure to assess depression (e.g., Beck

Depression Inventory, HADS-D, Centre for Epidemiologic Studies Depression Scale,

Depression Self-Rating Scale, Patient Health Questionnaire, etc.), reported a prevalence

rate of depression that ranged between 11.6% to 41.8% (Beal et al., 2007; Chwastiak et

al., 2002; Singer et al., 2009; Viner et al., 2014). This range is also within the prevalence

rate of HADS-D assessed depressive symptoms in our study (i.e., 30.5%).

There was a significant correlation between self-reported depressive symptoms

and medically diagnosed depression. Odds were higher for those individuals who

received a diagnosis of depression from their medical professional to also score above the

cut-off score on the self-reported measure (HADS-D) of depression. This is an important

finding in this study because the number of years before individuals received a diagnosis

of depression by their medical professional varied (i.e., from 1 year to 67 years with a

mean of 17.54 years), and researchers were unable to determine if participants'

depression remitted during the time of the survey. However, the odds were 2.45 times

higher for those individuals who received a depression diagnosis to also report depressive

symptoms on the HADS-D during the time of the survey. This may be due to two

reasons: first, PwMS continued to have depressive symptoms that did not remit from the

time they were first diagnosed. Second, self-identified depressive symptoms as measured

by the HADS-D may, in fact, reflect symptoms of MS rather than depression (e.g., items

such as "I feel as if I am slowed down"). It has been shown in the literature, that one of

the main concerns among healthcare professionals is the difficulty of separating MS

symptoms from depressive symptoms due to significant overlap of psychological and

neurological symptoms of the two diseases (Gunzler et al., 2015; Tylee & Gandhi, 2005).

Therefore, in order to prevent the misidentification of depressive symptoms as MS

symptoms, or vice versa, a stringent method is used in this present study to allocate

participants in depressed and non-depressed groups. Only those PwMS who received a

depression diagnosis by their medical professional and who also self-identified depressive

symptoms when assessed by HADS-D were considered depressed individuals in this

study. From the sample population, 87 (11.7%) participants reported receiving a medical

diagnosis of depression, as well as self-identified depressive symptoms during the time of

this survey.

In our study, 104 out of 191 PwMS who received a depression diagnosis prior to

the survey did not self-report depressive symptoms during the time of the survey. This

difference in the number of people reporting symptoms is because their symptoms may

have remitted from the time they were medically diagnosed to when the survey was

conducted. Therefore, if we had used only medically diagnosed depressed participants as

a sufficient criterion to compare with non-depressed participants, the results of the

analyses may not have been an accurate representation of the association of depression

with demographic and clinical variables. For example, the direction on the MSIS-29

states, "the following questions ask for your views about the impact of MS on your day-

to-day life during the past two weeks." Whereas, the item on the survey that asked

participants if they had a depression diagnosis, did not ask them if they had depression

during the time of the survey which may have explained the association of depression

with perceived difficulty. Only the HADS-D could assess if participants had depressive

symptoms during the time of the survey as according to the direction, participants are

asked to, "tick the box beside the reply that is closest to how you have been feeling in the

past week." However, a confirmed diagnosis of depression was not possible through

HADS-D due to the above-mentioned issues related to symptom overlap with MS.

Therefore, considering either medically diagnosed depression or HADS-D alone to find

predictors of depression was thought to be an inadequate approach when identifying participants as depressed or non-depressed in this study.

This study revealed that older adults with MS, whether they have self-identified depressive symptoms, a depression diagnosis by a medical professional, or both, had significantly lower levels of social support, and higher levels of perceived disability compared to those who did not have depression. Mid to high-level relationships were reported in this study between physical comorbidities and medically diagnosed depression, with a higher number of physical comorbidities showing a greater association with depression. Higher levels of perceived disability associated with depression in PwMS. Lower levels of social support were associated with depression. This is an important finding in this study because the literature showed that the presence of one or more physical comorbidities, low levels of social support, and high levels of perceived disability were significantly associated with depression (Aghaei et al., 2016; Costa et al., 2012; Marrie et al., 2008; Marrie & Horwitz, 2010; Mohr et al., 2004; Smith & Young, 2000).

When compared based on gender, men were found to self-identify depressive symptoms and were diagnosed with depression more than women. This is a significant addition to the MS literature because this result is contrary to the findings from most studies of the general population as well as the primary care population, including PwMS (Di Marco et al., 2006; Kessler, 2006; Magyari et al., 2014; Piccinelli & Wilkinson, 2000). One of the possible reasons behind such result may be that physicians are focusing more on asking questions related to depressive symptoms to male individuals because

physicians are aware of high suicide rate in males and understand that men may be more vulnerable to depression. Although according to Vafaei, et al., (2016), gender roles have been an important determinant in expression and experiencing of depressive symptoms, it cannot be assumed for certain that those male individuals who do not conform to masculine social roles were less depressed than those who did. It may also be possible that men are becoming more aware and comfortable sharing their emotional state with their medical professional and enhancing help seeking behaviours which led to more diagnosis of depression. Adaptive help seeking behaviours for depression among men are discussed by researchers Addis, and Mahalik, (2003).

PwMS who had to retire early due to their MS, compared to those who did not, were also found to have both a medical diagnosis of depression as well as self-reported depressive symptoms. This finding supports various research studies that also showed that early retirement is associated with depression in individuals from the general population and those with MS (Karpansalo et al., 2005; Orlewska et al., 2005; Rice et al., 2011; Shih et al., 2016).

There were some variances found in terms of self-identified depressive symptoms and medically diagnosed depression. Older adults who self-identified depressive symptoms also had significantly higher levels of physical disability, while medically diagnosed depression was not significantly associated with physical disability. This may be because some symptoms (e.g., fatigue, low energy) of physical disability are a result of MS and may not be due to depression, even though MS and depression share those same symptoms. Another potential explanation may be that some items of BI measured the

perceived difficulty of the participants. This is because the participants completed the questionnaire themselves instead of their health care provider. It may be that individuals' view on their own self-reported physical limitations of their performance was associated with self-reported depressive symptoms. Whereas, when PwMS were objectively assessed by a medical professional for depression, self-reported physical disability was found to have no significant association with depression. If we assume that the self-reported depressive symptoms are a representation of MS and not depression, which is why physical disability was not associated with self-reported depression symptoms, then, this mismatch may also be due to a mechanism called response shift. According to Schwartz, and Sprangers, (2009), response shift alludes to the change in the meaning of one's self-evaluation of a construct by changing in their internal standards of measurement, by changing their values and priorities, or changing their definition of the construct. For example, a person with who believed running a 10K was their definition of "being fit," may change their definition after being diagnosed with MS or living with MS for 20 years. This recalibration and redefinition may be the reason why medically diagnosed depressed and non-depressed participants did not differ on physical disability physical disability as their definition of physical disability changed.

In terms of age, younger PwMS were more depressed according to the self-report questionnaire (i.e., HADS-D). Results show that advancing age is not significantly associated with depression, and in fact it is the opposite. The age group of our cohort is quite varied (i.e., 55 years and over) and it is understood that a 55-year-old with MS may not have similar reasons for their depressive symptoms compared to a much older (e.g.,

65 to 70 years) person with MS. However, the significant association between depressive symptoms and age in older PwMS supports the broader conclusions of other studies from the literature on the general older population as well as in PwMS that age is associated with impacts mood (Leach et al., 2008; Rodda et al., 2011; Seyed Saadat et al., 2014). Our result on younger adults in the older population being more are affected by mood or that advancing age does not necessarily impact mood is also supported by others in MS population (Patten, Metz, & Reimer, 2000). As Kneebone et al., (2003) reported in his research study that older adults (age 65 years and older) in fact seemed to be less vulnerable to depression may be because they are less emotionally responsive. It also supports the view of Ploughman et al., (2012) that older adults learned to live and cope with MS for many years and hence the MS related changes do not impact their mood. Irrespective of these associations, various aspects of depressive symptoms can fluctuate over time. A three-year longitudinal study by Arnett and Randolph (2006) revealed that symptoms such as sadness and irritability fluctuated more than symptoms such as worthlessness, inappropriate guilt, sleep, and appetite. Therefore, several factors may have played a role in low mood, whereby age had a significant association with self-reported depressive symptoms during the time of the survey, whereas, age did not have any association with medically diagnosed depression. Also, it must be noted that although older age was related to greater self-reported depressive symptoms, length of MS or disease duration was not. This finding is consistent with Beal et al. (2007), who found that the length of MS did not influence self-reported depression over a period of 7 years. This finding was also in accord with Arnett and Randolph (2006), who demonstrated that symptoms of depression were quite stable over time.

In terms of financial condition, the literature shows that there is an association between low financial status and depression in the general population as well as specifically in PwMS (Butterworth et al., 2009; Green et al., 2007; Kobelt et al., 2006; Mirowsky & Ross, 1999; Orlewska et al., 2005; Wang et al., 2010). In support of the current literature, findings from this study revealed that people who reported not having enough money were more likely to report depressive symptoms on the HADS-D questionnaire than those who noted having enough money. This finding is similar to Marrie et al. (2009) who reported that lower levels of income were associated with an increased risk of depression. There were no significant association noted between low financial levels and medically diagnosed depression in this population.

As for the relationship between the type of MS and depression, even though we dichotomized progressive versus non-progressive MS like Beal et al. (2007), we did not find that progressive forms of MS were related to having depression as Beal and colleagues did. However, the literature on rates of depression in people with RRMS and progressive MS provides mixed results (Feinstein et al., 2014).

There were some variations noted in terms of self-reported depressive symptoms and depression diagnosed by a medical professional. There were more PwMS who self-reported depressive symptoms during the time of the survey than persons who were medically diagnosed with depression. This may be due to two possible reasons. First, the self-reported symptoms of depression identified by PwMS through the HADS-D questionnaire may be symptoms of MS and not depression which may be due to the overlap of somatic symptoms found in MS and depression. A similar view was shared by

Feinstein et al. (2014) who acknowledged the challenges faced by researchers and clinicians when defining and diagnosing depression in the context of MS noting that there are major overlaps in psychiatric and neurological symptoms. The second reason may be due to the under-diagnosis of depression in general and primary care population. While 227 PwMS meet criteria for depression according to the self-report measure (i.e., HADS-D), 191 people had a confirmed diagnosis. Therefore, depression was not diagnosed in 36 people who self-reported depressive symptoms. This finding is also supported by Marrie et al. (2009) who found that potentially undiagnosed depression was frequent in PwMS. Their research showed that 15% of PwMS who did not report depression as a mental comorbidity, had scored above the cut-off (≥ 21) on the Center for Epidemiologic Studies Depression Scale (CES-D) indicating probable major depression. As such, they concluded that depression frequently remains undiagnosed in PwMS. Regardless of whether depression was self-identified or diagnosed by a medical professional, exploring possible predictors of depression is thought to help clinicians to routinely assess for mood disorders in at-risk PwMS which in the long run may prevent depression.

5.1b. Predictors of Depression

As discussed above, due to the frequent overlap of the psychiatric and neurological symptoms of MS with those of depression, a more stringent method was employed to define depression in order to minimize false positive cases. In this section, depression is denoted by both the presence of self-reported depressive symptoms according to the cut-off score (≥ 8) on HADS-D and a diagnosis of depression as provided by the participant's medical professional.

Physical Comorbidities

The variable "total number of physical comorbidities" was the strongest independent predictor of depression among older PwMS according to this study. According to the study conducted by Marrie et al. (2008), out of 8,953 PwMS, 3,280 (36.7%) accurately self-reported comorbid conditions, and the three most common conditions reported were hypercholesterolemia (37%), hypertension (30%), and arthritis (16%). Another research study that investigated the effect of comorbidities in HRQoL in 949 PwMS (mean age 48.62 years) found hypertension (17.8%) and hypercholesterolemia (12.4%) to be the most common types of comorbid physical conditions (Berrigan et al., 2016). In our study, out of 743 PwMS, 633 (85.2%) participants reported having at least one comorbid condition and the most common type of condition reported was hypertension (35.7%), followed by hypercholesterolemia (26.6%) and arthritis (24.5%). Therefore, our study also supports the claim that PwMS are most commonly diagnosed with hypertension, hypercholesterolemia, and/or arthritis. Various research studies have shown that having a chronic condition makes a person vulnerable to depression (Becofsky et al., 2013; Hughes et al., 2014). Through a systematic review of over 249 studies by Cohen et al. (2015) it was demonstrated that there is an increase in the prevalence of comorbid conditions in PwMS. As demonstrated by the research conducted by Marrie et al., (2009), our study supports that the interaction of a comorbid disease and depression may pose challenges in the diagnostic process and the management of depression, as well as worsens MS-related symptoms. Similar to the findings from the literature regarding various chronic conditions and their impact on mood, results from our study suggest that

psychical comorbidities (e.g., arthritis, hypertension, and hypercholesterolemia) are risk-factors for depression in older PwMS.

Social Support

Consistent with most of the MS and social support literature, our study found that greater perceived social support was associated with less depression above and beyond the variance accounted for by demographic and disease-related variables. This result is similar to the studies that were conducted with the general population, the primary care population, and specifically with PwMS across all ages as well as older adults (Bambara et al., 2011; Benmarhnia & Zunzunegui, 2014; Faramarzi et al., 2015; Grav et al., 2012; Hughes et al., 2014; Wu et al., 2013). Findings from our study are consistent with various studies conducted across the world suggesting that, irrespective of available resources, lack of social support remains one of the primary risk-factors of depression (Faramarzi et al., 2015; Fauth, Gerstorf, Ram, & Malmberg, 2012; Feinstein, 2011; Siegert & Abernethy, 2005). Evidence from this study confirms that social support is beneficial and is needed to reduce the risk of developing depression in older PwMS. The stress-buffering hypothesis, proposed by physician and epidemiologist John Cassel and psychiatrist Sidney Cobb in 1976 suggests that individuals who have more social support are better protected from the negative consequences of stressors such as illness, life-events, and developmental transitions (Cassel, 1976; Cobb, 1976). Social support also helps individuals to be active and have a less sedentary lifestyle. For example, having commitments to attend a function, a social or religious ceremony, or going out for a group stroll down to the park urge individuals to engage in physical activities. As such, social

support may inform positive health behaviours in older PwMS. Social participation like attending a community yoga class or a meet-up group may promote healthy living and increase feelings of belonging, which may also be a protective factor against depression (Chronister, Johnson, & Berven, 2006; Grossman et al., 2010; Turner & McLaren, 2011). The view that depression negatively impacts social participation is also supported by Beekman et al. (2002) who conducted a prospective community-based study on older PwMS (55 - 85 years) in the Netherlands. Therefore, we can determine that low social support is a significant risk factor for depression in older PwMS.

<div align="center">Perceived Disability</div>

Perceived disability is a significant predictor of depression in our cohort. Literature on perceived disability suggests that depression impacts one's self-efficacy which is a determining factor in the development of disability in the primary care population (e.g., chronic pain, arthritis) (Arnstein et al., 1999; Menendez et al., 2015; Nabolsi et al., 2015; Roh et al., 2012; Shnek et al., 1997). In individuals with fibromyalgia, chronic fatigue syndrome, and arthritis, research showed the positive impact of treating depression on one's perception of pain and/or functional limitations (Becofsky et al., 2013; Menendez et al., 2015; Wolfe & Michaud, 2009). Therefore, PwMS who share similar symptoms as with people with arthritis may also have similar benefits from the treatment for depression. In PwMS, Smith and Young (2000) showed similar results wherein depressed PwMS using BDI and HADS criteria were three times more likely than non-depressed PwMS to perceive their disability as being greater than their physician's assessment of their disability. Our result, on the other hand, makes a

unique and important contribution to the literature because it shows that PwMS who perceive themselves as disabled are at a greater risk of having depression. Our finding that perceived disability is a predictor of depression supports Beck's Cognitive Theory of Depression by Allen (2003), which states that depression is a result of one's view of oneself, rather than one's negative view of oneself being the result of depression.

Low social support, higher levels of perceived disability, and physical comorbidities are risk factors for depression in older PwMS. Therefore, those individuals who have been living with MS for over two decades and have learned coping strategies to deal with their disease may still develop depression if they are at risk due to one or more of the above factors. As such, those older PwMS who report a lack of social support, have one or more secondary chronic condition/s along with MS, and/or have a high perceived level of disability should be regularly screened for depression through a self-report measure as well as structured and/or semi-structured interviews.

5.2 Strength of the study

One of the main strengths of this study is its large sample size that adequately represents the national population of older people with MS in Canada. Participants were recruited from eight different provinces across Canada which also speaks to the geographical generalizability. 921 PwMS were initially contacted, of whom 743 (81%) participants completed and returned the questionnaire. This is a relatively strong indication of older peoples' desire to find answers to their difficulties due to MS. It also reflects the need to provide older PwMS with new information as they are equally keen on learning about their disease even though they have lived with it for over 20 years.

Participants were from various socioeconomic categories, educational levels, financial

backgrounds, and levels of disability. The first two analyses in this research study used

the large population and had a robust representation of depressed and non-depressed

participants.

This study used reliable and valid instruments to assess depression, social support,

and perceived disability. In terms of measuring depression, research shows that HADS is

a popular instrument used in people with primary health care issues (Al-Gamal, 2015;

Honarmand & Feinstein, 2009; Singer et al., 2009). There is a high overlap of the somatic

symptoms of depression with that of MS. Therefore, various research studies prefer using

HADS over other tools like the Beck Depression Inventory (BDI) to measure depression

as the items of HADS are not heavily based on somatic symptoms (e.g., pain, fatigue,

appetite, sleep) (Feinstein et al., 2014; Tylee & Gandhi, 2005). As such, participants'

responses on HADS can be assumed to be a relatively accurate representation of their

actual mood as HADS produces minimal false positive cases. This was primarily

supported by a meta-analysis (i.e., 50 studies) that demonstrated the diagnostic validity of

the HADS in cancer and palliative settings (Mitchell, Meader, & Symonds, 2010).

Various researchers described the difficulties in differentiating depressive symptoms from

clinical symptoms of MS due to the psychiatric and neurological overlap between the two

diseases. As such, this study used a more stringent method to be able to accurately

determine depression and avoid false positive cases due to symptom overlap (Feinstein et

al., 2014; Gunzler et al., 2015). The depressed cohort had a diagnosis of depression

provided by their medical professional and their self-report scores on the depression

measure were above the cut-off score (HADS-D ≥8). The initial analyses were conducted on individuals with self-reported depression and medically diagnosed depression separately. This was done to examine the significant association of, a., medically diagnosed depression with demographic and clinical variables, and b., self-reported depressive symptoms with demographic and clinical variables. The final analysis to examine the predictors of depression was done with individuals who had both self-reported depressive symptoms as well as medically diagnosed depression.

This study is the first national survey that investigated two aspects of disability (i.e., physical disability and perceived disability) to explore which of the two types of disability is a risk factor for depression in older PwMS. While physical disability is measured by limitations in functional activities, perceived disability takes into consideration an individuals' insight of their limitations posed by MS.

Most research studies focus on individuals that have been recently diagnosed with MS and who are generally much younger than 55 years. This study provides insight into the factors that interfere with healthy aging in older PwMS by recognizing the risk-factors for depression in this population. Depression may complicate MS symptoms. As such, understanding and knowing the risk-factors will not only prevent depression but also help manage MS-related symptoms. Over the years, participants of this study may have acquired self-tested strategies that enabled them to live with an unpredictable chronic disease for more than 20 years. At the same time, these participants also face unique challenges due to their advancing age that may be different from those faced by the

younger population. Therefore, exploring the factors associated with depression in older PwMS is an essential aspect in promoting healthy aging.

Frequently, researchers faced difficulties recruiting a large sample size, but in our study, the use of postal service to send out the questionnaires, and pre-paid reply envelopes were some helpful strategies that resulted in uniform recruiting of a representative sample.

5.3 Limitation of the study

The main limitation of the study is the cross-sectional design that prevents us from forming causal relationships between variables. The sample size was not evenly distributed across depression. Non-depressed participants represented three times that of depressed participants in our sample population. This may be due to lack of motivation (amotivation) in depressed participants to self-identify in order to be recruited as a potential research participant. Amotivation and lack of interest are symptoms of depression that are often seen as a barrier to research participation. In a systematic review, researchers found 15 studies that stated that the decision to participate in a research study depends on patient's health at the time when they are requested to participate (Hughes-Morley, Young, Waheed, Small, & Bower, 2015). Therefore, health concerns of participants may have been a challenge in this primary care population during recruitment.

Another significant challenge that is especially faced by researchers who mail their research measures is the inability to control the testing situation. Although the

questionnaire set contained instructions on how to complete the questionnaire (e.g., taking rest between chapters), participants may have used their own discretion on how they completed the questionnaire package (Ploughman et al., 2012). This may be influenced by participant's fatigue, pain, mood, or external factors. Also, discussing responses with another family member may skew the data and may not reflect participants' own reactions as well.

One of the major limitations of self-report questionnaires is that there is no way to determine whether respondents give honest answers to questions. The resistance to report accurately on mental health questions may also be a major limitation of self-report questionnaires and participants may show social desirability bias (Grimm, 2010).

Canada is a multi-cultural nation. Therefore, the research population may have had a large distribution of different ethnicities. Culture and race may play a significant role in interpreting psychopathology. This may create reference bias, which occurs when questionnaires are influenced by differing standards of comparison. A person deciding whether he or she is depressed must envision a mental image of a depressed person which he or she can compare with. For example, a meta-analysis was conducted to examine the racial/ethnic differences in the factor structure of the Center for Epidemiologic Studies Depression Scale (CES-D) to screen for depression. Results from the analysis cautioned clinicians and researchers when using the CES-D to screen for depression because symptoms of depression may be presented differently by different racial/ethnic groups (Kim, DeCoster, Huang, & Chiriboga, 2011).

Items of HADS are based on a Likert scale. As such, the responses are subjective and depend on the participant's ability to conceptualize each item that corresponds to their symptoms of depression. Although rating scales allow participants to provide more nuanced responses than a simple "yes-no," using rating scales may also be problematic. Participants may interpret and use scales differently. For example, one person may rate 8 on a 10-point scale, and with the same opinion, someone else may rate 6/10 because they interpret the meanings attached to the scales differently (Austin, Deary, Gibson, McGregor, & Dent, 1998).

According to Bocerean and Dupret (2014), symptoms of depression and anxiety often overlap. Therefore, the scores on the HADS-D component may not reflect the true depression score of participants. Also, the authors noted that HADS-D measures only the anhedonic symptoms (i.e., symptoms that reflect despondency and inability to engage in activities that they did before) of depression. Therefore, people who exhibit more somatic or cognitive symptoms (e.g., fatigue, low energy, change in appetite or sleep, and concentration and memory problems) may not score high on HADS-D. As such, the somatic symptoms that an individual may verbalize to their physician may be interpreted as symptom of MS and not depression. In a systematic examination of the diagnostic performance of HADS and BDI in a sample of 298 French participants, Sultan, Luminet, and Hartemann (2010) reported that the depression subscale of the HADS performed poorly. They also noted that according to their result, along with depressed mood, both negative thoughts and anxiety are important symptoms that clinicians need to consider for the correct identification of clinical depression in chronic illnesses. As such, Sultan et al.

(2010) recommended using the total score when using the HADS. While some studies supported the used of HADS-D, others recommended using the complete HADS to screen for depression. In order to deal with this uncertainty, our research study only considered those participants whose score on HADS-D was above the cut-off and who had a depression diagnosis from a medical professional.

There was no way to confirm if the diagnosis of depression provided by the medical professional was given after conducting a brief interview with the participants to confirm depression. It was also a form of participants reported depression diagnosis that they noted were given by medical professional. In terms of gender, a limitation is that there may have been some confounding factors involved when defining gender and sex of the participants.

Lastly, while the Barthel Index measures functional limitations by observing performance, the directions on the assessment instructs participants to "choose the scoring point for the statement that most closely corresponds to the patient's current level of ability for each of the following 10 items. Record actual, not potential, functioning." However, our survey does not clarify this aspect. As such, depending on the participant's understanding, items on the Barthel Index may still be answered as perceived difficulties as they are completed by PwMS and not by their physician.

5.4 Clinical Implications

Given the statistically significant findings of this study, it is important to consider their implications. Depression is an important factor that needs to be monitored on a

regular basis by an individual's health care provider. PwMS may not report symptoms

that are exclusive to depression like those that emulate symptoms of MS (e.g. fatigue,

cognitive difficulties, and pain), and they may continue living with the symptoms. This

can worsen MS, as well as complicate the aging process. The study found that social

support, perceived disability, and physical comorbidities were strong independent

predictors of depression in older PwMS. As such, if a person with MS reports low social

support, high perceived disability and/or has one or more physical comorbidities (e.g.,

hypertension, hypercholesterolemia, arthritis), then he/she is at risk of depression.

Therefore, during an intake session, or a regular medical visit, if a person reports one or

more above-mentioned variables as a potential concern, then his/her health care provider

must screen for depression with a structured and/or semi-structured interview and a

screening tool. Therefore, this research is of great clinical importance as it reflects, and

substantiates, the need for regular assessment of depression in older PwMS.

This study acknowledges the difficulty in differentiating depressive symptoms

from that of MS symptoms due to the neurological and psychological symptom overlap

between the two diseases. It shows that self-reported depressive symptoms are strongly

associated with physical disability, while medically diagnosed depression is significantly

associated with physical comorbidities. Due to the difference in the variables and their

association with self-reported versus medically diagnosed depression, medical

professionals are encouraged to use clinical interviews and/or clinical impressions as well

as screening tools when diagnosing depression in PwMS.

Timely treatment of depression in older adults with MS can be an effective way to tackle economic burdens related to depression and the management of MS symptoms. For example, perceived disability (i.e., the perception of disability caused by MS) is associated with depression (Smith & young 2000). Therefore, providing therapy (e.g., Cognitive Behaviour Therapy) to challenge one's perception and unhelpful ways of thinking can be helpful in managing and preventing depression in PwMS (Clancy, Drerup, & Sullivan, 2015). Policy makers, particularly those of programs in community and hospitals, neurologists, and psychologists, as well as allied healthcare professionals, could benefit from being made aware of these associations and risk-factors of depression.

Depression is alarmingly common among primary care settings, which makes it difficult for PwMS to receive treatment for mood disorders from specialized professionals such as clinical psychologists. There is a significant need for an interdisciplinary team in primary care settings not only to provide holistic care to patients but also to promote health care cost effectiveness and time effectiveness. A collaborative care approach for depression for PwMS using primary care facilities will be beneficial. According to Gunn et al. (2006), collaborative care is a comprehensive intervention strategy that includes an interprofessional approach to patient care. It consists of a structured disease management plan, scheduled patient follow-ups, and increased interprofessional interactions within the same primary care setting.

It must be emphasized that due to the non-experimental nature of this study, causal links between self-reported depressive symptoms, or medically diagnosed depression and demographic and clinical variables cannot be established. As such,

caution must be used when using the results of this study to inform intervention strategies. Significant results from an experimental study could help shape necessary prevention and intervention strategies for depression in older PwMS.

5.5 Directions for Future Study

While this study has revealed many important findings, it has also set a foundation for future research. Future research can focus on examining the differences between the prevalence of depression and point-prevalence of depression to see if there are any specific factors present at a particular time in one's life that make one more vulnerable to depression.

One significant aspect of treatment planning that needs further understanding is that PwMS continue to struggle with depression and as such, they require constant screening and intervention for depression. Due to the overlap of symptoms in MS and depression, it is sometimes tricky to skillfully differentiate depression symptoms from MS symptoms. Therefore, future research should also inquire how an individual was diagnosed with depression by their medical professional. For example, if they received a diagnosis based on self-report measures alone, then there may be a possibility that the presented symptoms are not an accurate reflection of a mood disorder.

Future studies can also focus on exploring different aspects of social support in older PwMS. For example, perceived social support, utilized social support, number of supports, satisfaction with social support and type of social support (e.g., support from

spouse versus community members) may give a better understanding of what aspect of social support plays a more crucial role in preventing depression in older PwMS.

As it is a cross-sectional study, causal associations between depression and other variables cannot be made. Therefore, one must be careful when interpreting the findings and building intervention strategies based on the results of this study. While this study has shown that there are relationships between depression, social support, perceived disability and physical comorbidities, conclusions cannot be drawn about the direction or time sequencing of these connections (e.g., lack of social support and physical disability predicted depression, but depression could also predict lack of social support and physical disability). At the same time, the presence of other variables such as age and/or gender may explain depression and its relationship to social support or perceived disability. So, future research may consider the possibility of an experimental design with older PwMS. Significant results from an experimental study could help design prevention and treatment strategies for older PwMS with depression.

Future research can focus on evaluating health and lifestyle choices, and their interaction with mood which may also be helpful in determining treatment strategies.

5.6 Conclusion

Emerging evidence identifies that depression affects older PwMS and their ability to function productively with a chronic illness. The aim of this study was to determine the risk factors for depression in older PwMS. Depression and MS share several common psychological and neurological symptoms such as fatigue, pain, insomnia, cognitive

difficulties, and sleep disturbances which make the diagnosis of depression in PwMS

difficult for medical professionals. The association established with self-reported

symptoms of depression and clinical or demographic variables in PwMS may not be only

because of mood disorders but may also be due to MS. For example, the results of this

study found that there was a significant relationship between self-reported depressive

symptoms and age while the relationship between medically diagnosed depression and

age was not significant. Similar discrepancies were noted in terms of physical disability,

physical comorbidities, and financial conditions. Therefore, in order to overcome this

disparity, only those PwMS who had both self-reported symptoms of depression (i.e.,

above HADS-D cut-off) and a medically diagnosed depression formed the depressed

cohort for the predictive model. The results of the final analysis showed that low social

support, high perceived disability, and more physical comorbidities were significant

independent predictors of depression in older PwMS. MS cannot be entirely treated, but

the symptoms can be managed. However, depression is a treatable condition. Therefore,

prevention of depression by proper screening techniques, and timely treatment of

depression can help older PwMS live a productive life even with a chronic condition.

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Appendix 1

Variable Coding

Age	2011 – Year of birth of each participant

Gender	*Your gender?*
	    0: Female
	    1: Male

HADS-D	*Total score on HADS-D*
	    0: No Depressive Symptoms (score 0 – 7)
	    1: Depressive Symptoms (score 8 – 21)

Financial Situation	*Which statement best describes your financial situation?*
	    1: I have more than enough money to meet my needs so I can live
	    2: I have more than enough money to meet my needs so I can live
	    3: I have more than enough money to meet my needs so I can live
	Recoded:
	    0: Do not have money
	    1: Have money

Type of MS	*What type of MS were you diagnosed with?*
	    1: Unknown
	    2: Benign
	    3: Relapsing-Remitting
	    4: Other
	    5: Primary-Progressive
	    6: Secondary-Progressive
	    7: Progressive-Relapsing
	
	The two most frequently reported types: Relapsing-Remitting and Primary-Progressive
	Recode (a)
	    0. No relapsing-remitting
	    1. Relapsing-Remitting

	Recode (b)
	   0. No primary-Progressive
	   1. Primary-Progressive

Early Retirement due to MS	*Did you retire early or have to stop working because of your MS?*
	   0: No
	   1: Yes

Length of MS	2011 – Year when the participant was diagnosed with MS
Diagnosis of Depression as provided by a Medical Professional	0. No Diagnosis 1. Diagnosis
Presence of Depression (HADS-D $\geq$ 8 and medically diagnosed depression	0. Non-depressed 1. Depressed

Appendix 2

Ethics Approval

Health Research
Ethics Authority

Ethics Office
Suite 200, Eastern Trust Building
95 Bonaventure Avenue
St. John's, NL
A1B 2X5

May 23, 2014

Tanaya Chatterjee
Dept of Psychology
Memorial University

Dear Ms Chatterjee

Reference #14.103

Re: Health Lifestyle and Aging with MS – Canadian Survey

Your application received an expedited review by a Sub-Committee of the Health Research Ethics
Board and **full approval** was granted effective **May 23, 2014.**

This approval will lapse on May 23, 2015. **It is your responsibility to ensure that the Ethics
Renewal form is forwarded to the HREB office prior to the renewal date; you may not receive a
reminder, therefore the ultimate responsibility is with you as the Principle Investigator.** *The
information provided in this form must be **current to the time of submission** and submitted to the
HREB **not less than 30 nor more than 45 days** of the anniversary of your approval date.* The Ethics
Renewal form can be downloaded from the HREB website http://www.hrea.ca.

This is to confirm that the following documents have been reviewed and approved or
acknowledged (as indicated):

- Application approved

*The Health Research Ethics Board advises THAT IF YOU DO NOT return the completed Ethics
Renewal form prior to date of renewal:*

- *Your ethics approval will lapse*
- *You will be required to stop research activity immediately*
- *You may not be permitted to restart the study until you reapply for and receive approval to
  undertake the study again*

Lapse in ethics approval may result in interruption or termination of funding
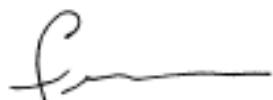email: info@hrea.ca   Phone: 777-8949   FAX: 777-8776

It is your responsibility to seek the necessary approval from the Regional Health Authority or other organization as appropriate. You are also solely responsible for providing a copy of this letter, along with your application form, to the Office of Research Services should your research depend on funding administered through that office.

Modifications of the protocol/consent are not permitted without prior approval from the Health Research Ethics Board. Implementing changes in the protocol/consent without HREB approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity. Request for modification to the protocol/consent must be outlined on an amendment form (available on the HREB website) and submitted to the HREB for review. This research ethics board (the HREB) has reviewed and approved the research protocol and documentation as noted above for the study which is to be conducted by you as the qualified investigator named above at the specified site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Health Research Ethics Board currently operates according to *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; ICH Guidance E6: Good Clinical Practice* and applicable laws and regulations. The membership of this research ethics board is constituted in compliance with the membership requirements for research ethics boards as defined by *Health Canada Food and Drug Regulations Division 5; Part C*
Notwithstanding the approval of the HREB, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

Sincerely,

Dr Fern Brunger, PhD (Chair Non-Clinical Trials)
Ms. P. Grainger, (Vice-Chair Non-Clinical Trials)
Health Research Ethics Board

For Office Use only: May 29, 2014

Appendix 3

Survey Questionnaire

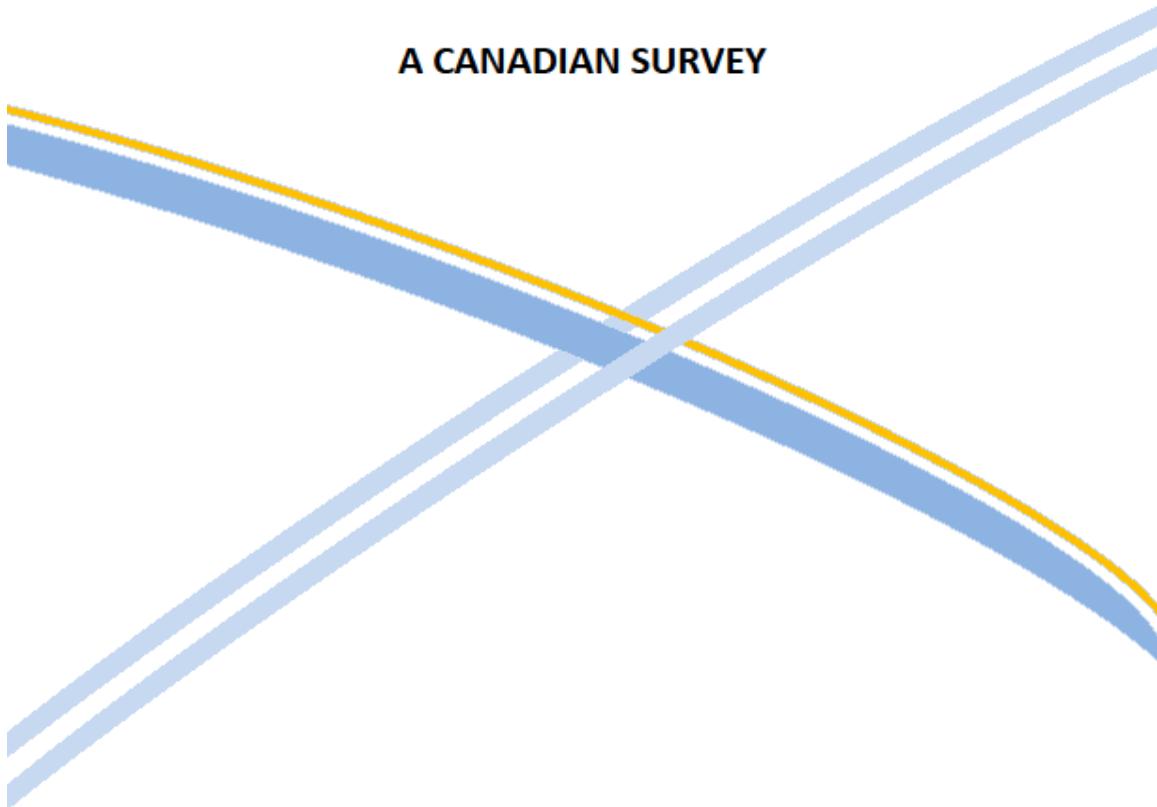

**LIVING LONG and HEALTHY
with MULTIPLE SCLEROSIS**

A CANADIAN SURVEY

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Thank you again for agreeing to complete this survey. Your input will assist in the development of programs that improve the quality of life of people with MS, as well as the development of a *Healthy Living Information Booklet* for MS Clinics. If you have any questions concerning the research project, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided if you have other questions. The research team can also help you complete this survey over the phone using the survey helpline number.

Any information you provide will be maintained in a secure manner. No one besides the investigator, Dr. Michelle Ploughman, and her research assistant will know how you answered the questions. All information about you will be kept secure in an office at the L.A. Miller Centre in St. John's, Newfoundland. Your name will not be used in this study and all information you provide is strictly confidential. Your participation in the survey is voluntary and will not affect your future care. There are no known benefits to participating in this study. Our pilot work indicated that there were no risks, discomforts or inconveniences associated with participating in this study.

This survey has been broken down into several sections and we encourage you to take breaks as needed when completing it. If you have any comments about particular questions, just write them on the survey. Once completed, use the self-addressed stamped envelope to send it back to us. We greatly appreciate your time and input into this project.

Sincerely,

Dr. Michelle Ploughman PT PhD

Study Sections

You and Your MS (5 pages)
Your Health (6 pages)
Your Activities (8 pages)
Your Thoughts and Feelings (7 pages)
Your Social Life (4 pages)
Your Opinions (1 page)

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CODE: _____

YOU AND YOUR MS

1. Your Postal Code _____

2. Your Gender   □ Male   □ Female

3. Your Year of Birth   _____

4. Your height: _____   cm / in   *(Please circle unit of measure)*

5. Your weight: _____   lbs / kg   *(Please circle unit of measure)*

6. What is the highest grade of education that you have completed?

Grade: _____

7. What post-secondary training have you completed (if any)? *Check all that apply.*

□ 1-year college program
□ 2-year college program
□ 3-5 year college or university program
□ University master's degree program
□ University doctorate degree program

8. What is your living situation? *Check all that apply.*

□ I live alone
□ I live with my partner
□ I live with my children
□ I live with a friend or extended family

9. In what type of home do you live?

☐ I live in a house/apartment/condominium

☐ I live in an assisted living complex

☐ I live in a long-term care facility

10. Do you receive any home or personal care services? *Check all that apply.*

☐ I do not receive any home or personal care services

☐ I receive housekeeping services

☐ I receive visits for personal care assistance

☐ I receive personal care from someone staying in my home or from employees in my facility/complex

11. How well-adapted is your home to meet your needs associated with having MS? (Check ALL that apply)

☐ My home is not adapted at all

☐ My home is somewhat adapted

☐ My home is completely adapted

☐ I do not require any special adaptations

12. Which statement best describes your 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

☐ I *do not have enough money* to meet my needs so I can live the way I want

13. Do you have any private health insurance or disability insurance to pay for your expenses?

☐ Yes

☐ No

14. If you answered yes to the previous question, how much do you claim on your insurance each year?

☐ I claim less than $1000 on my insurance each year
☐ I claim between $1001 and $5000 on my insurance each year
☐ I claim between $5001 and $10 000 on my insurance each year
☐ I claim over $10 000 on my insurance each year

15. Has your province ever funded you to pay for any of the following?

Home Care	☐ Yes	☐ No
Equipment	☐ Yes	☐ No
Home Renovations	☐ Yes	☐ No
Medications	☐ Yes	☐ No

16. When were you officially diagnosed with MS by a doctor?

Date:_____

17. When did you first experience symptoms of MS (if known)?

Date:_____

18. What type of MS were you initially diagnosed with?

☐ Unknown   ☐ Primary-Progressive
☐ Benign   ☐ Secondary-Progressive
☐ Relapsing-Remitting ☐ Progressive-Relapsing
☐ Other (please specify):_____

The following questions ask about your views about the impact of MS on your day-to-day life **during the past two weeks.** For each statement, please circle the one number that **best** describes your situation. Please answer all questions.

In the past two weeks, how much has your MS limited your ability to...	Not at all	A little	Moderately	Quite a bit	Extremely
19. Do physically demanding tasks?	1	2	3	4	5
20. Grip things tightly (e.g. turning on taps)?	1	2	3	4	5
21. Carry things?	1	2	3	4	5

In the past two weeks, how much have you been bothered by...	Not at all	A little	Moderately	Quite a bit	Extremely
22. Problems with your balance?	1	2	3	4	5
23. Difficulties moving about indoors?	1	2	3	4	5
24. Being clumsy?	1	2	3	4	5
25. Stiffness?	1	2	3	4	5
26. Heavy arms and/or legs?	1	2	3	4	5
27. Tremor of your arms or legs?	1	2	3	4	5

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| In the past two weeks, how much have you been bothered by...	Not at all	A little	Moderately	Quite a bit	Extremely
28. Spasms in your limbs?	1	2	3	4	5
29. Your body not doing what you want it to do?	1	2	3	4	5
30. Having to depend on others to do things for you?	1	2	3	4	5
31. Limitations in your social and leisure activities at home?	1	2	3	4	5
32. Being stuck at home more than you would like to be?	1	2	3	4	5
33. Difficulties using your hands in everyday tasks?	1	2	3	4	5
34. Having to cut down the amount of time you spent on work or other daily activities?	1	2	3	4	5
35. Problems using transport (e.g. car, bus, train, taxi, etc.)?	1	2	3	4	5
36. Taking longer to do things?	1	2	3	4	5
37. Difficulty doing things spontaneously (e.g. going out on the spur of the moment)?	1	2	3	4	5

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YOUR HEALTH

48. Place a mark on the line that best shows how you feel about your own health state today.

Worst
Imaginable
Health State

_____

Best
Imaginable
Health State
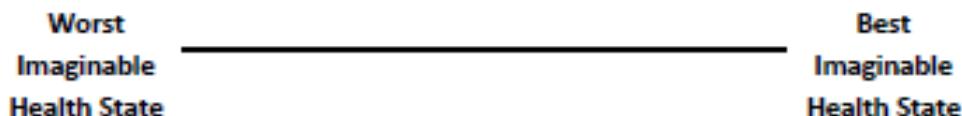
49. Please indicate any health conditions that you have been diagnosed with by a health professional by placing a tick in the boxes below and writing the year you were diagnosed with each condition in the space provided next to each. Please check all that apply.

□ high blood pressure _____

□ high cholesterol _____

□ cataracts _____

□ depression _____

□ arthritis _____

□ heart disease _____

□ skin cancer _____

□ thyroid disease _____

□ lung disease _____

□ irritable bowel syndrome _____

□ diabetes _____

□ anxiety _____

□ peptic ulcer disease _____

□ breast cancer _____

□ glaucoma _____

□ vitamin B12 deficiency _____

□ peripheral vascular disease _____

□ rheumatoid arthritis _____

□ anemia (low iron) _____

□ hip replacement _____

□ fibromyalgia _____

□ knee replacement _____

□ inflammatory bowel disease _____

□ kidney disease _____

□ uveitis _____

(continued on next page...)

□ colon cancer _____   □ rectal cancer _____

□ bipolar disorder _____   □ systemic lupus erythematosus _____

□ liver disease _____   □ Sjögren's syndrome _____

□ lung cancer _____

50. If you checked any of the conditions listed, please place a mark on the line below to indicate how concerned you are about them.

Not at all   **Extremely**
concerned _____ **Concerned**

Below are common tasks associated with day-to-day living. Please answer by placing a check next to the *best possible response* for each task. If you feel that your abilities fall between two responses, you may check both boxes that you think apply.

51. Eating:
□ I am not able to eat without help
□ I need help cutting, spreading butter, etc., or need a modified diet
□ I am completely independent

52. Bathing (tub or shower):
□ I need help
□ I am completely independent

53. Grooming (face/hair/teeth/shaving):
□ I need help
□ I am completely independent

54. Dressing:
- ☐ I need help
- ☐ I need help but I can do about half unaided
- ☐ I am completely independent (including buttons, zips, laces, etc.)

55. Bowels:
- ☐ I have frequent accidents (or need to be given enemas)
- ☐ I have occasional accidents
- ☐ I have no accidents

56. Bladder
- ☐ I have frequent accidents or need help to manage a catheter
- ☐ I have occasional accidents
- ☐ I have no accidents or use a catheter that I can manage myself

57. Toilet Use:
- ☐ I need help
- ☐ I need some help, but can do some things alone
- ☐ I am completely independent (on and off, dressing, wiping)

58. Transfers (bed to chair and back)
- ☐ I am not able to do that
- ☐ I need the help of one or two people
- ☐ I need minor help (verbal or physical)
- ☐ I am completely independent

59. Mobility (on level surfaces) (check ALL that apply)

☐ I cannot move around

☐ I can use my wheelchair on my own for <u>less than</u> 150 feet
☐ I can use my wheelchair on my own, including corners, for <u>more than</u> 150 feet

☐ I can walk with the help of one person for <u>less than</u> 150 feet
☐ I can walk with the help of one person for <u>more than</u> 150 feet

☐ I can walk on my own, with or without an aid (cane or walker) for <u>less than</u> 150 feet
☐ I can walk on my own, with or without an aid (cane or walker) for <u>more than</u> 150 feet.

60. Stairs:

☐ I am not able to climb stairs

☐ I need help or I use a stair lift

☐ I am completely independent

61. We would like to know your experiences with health care professionals. In the blanks below, please list any health care professionals that you can recall working with (such as a neurologist, family doctor, therapist, personal trainer, nurse, social worker, etc.). Then please rate how well they helped with your MS on the 1 – 5 scale next to each.

Health Care Professional	Not at all Helpful				Extremely Helpful
_____	1	2	3	4	5
_____	1	2	3	4	5
_____	1	2	3	4	5
_____	1	2	3	4	5
_____	1	2	3	4	5
_____	1	2	3	4	5

62. If you have been prescribed medications now or in the past for your MS please record them below and rate their effectiveness on the 1 – 5 scale next to it.

Medication	Not at all Helpful				Extremely Helpful
_____	1	2	3	4	5
_____	1	2	3	4	5
_____	1	2	3	4	5
_____	1	2	3	4	5
_____	1	2	3	4	5

63. If you have taken any supplements and/or alternative treatments for your MS now or in the past (anything not given to you through a doctor's prescription such as liberation treatments, bee sting therapy or herbal supplements), please record them below and rate their effectiveness on the 1 – 5 scale next to it.

Alternative therapy	Not at all Helpful				Extremely Helpful
_____	1	2	3	4	5
_____	1	2	3	4	5
_____	1	2	3	4	5
_____	1	2	3	4	5
_____	1	2	3	4	5

YOUR ACTIVITIES

Below are common activities associated with day-to-day living. Please answer by placing a check next to the *best possible response* for each activity.

In the last three months how often have you undertaken:

64. Preparing main meals (breakfast, lunch, dinner):

☐ never
☐ less than once a week
☐ 1-2 times a week
☐ most days

65. Washing up (dishes, kitchen counters):

☐ never
☐ less than once a week
☐ 1-2 times a week
☐ most days

66. Washing clothes:

☐ never
☐ 1-2 times in three months
☐ 3-12 times in three months
☐ at least weekly

67. Light housework (sweeping, dusting, etc.):

☐ never
☐ 1-2 times in three months
☐ 3-12 times in three months
☐ at least weekly

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68. Heavy housework (vacuuming, scrubbing floors):

☐ never
☐ 1-2 times in three months
☐ 3-12 times in three months
☐ at least weekly

69. Local shopping:

☐ never
☐ 1-2 times in three months
☐ 3-12 times in three months
☐ at least weekly

70. Social outings (group meetings, visiting family or friends, going to the movies, etc.):

☐ never
☐ 1-2 times in three months
☐ 3-12 times in three months
☐ at least weekly

71. Walking outside for more than 15 minutes:

☐ never
☐ 1-2 times in three months
☐ 3-12 times in three months
☐ at least weekly

72. Actively pursuing a hobby (knitting, scrapbooking, drawing, playing a musical instrument, using a computer, etc.):

☐ never
☐ 1-2 times in three months
☐ 3-12 times in three months
☐ at least weekly

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73. Driving a vehicle / going on a bus:

☐ never
☐ 1-2 times in three months
☐ 3-12 times in three months
☐ at least weekly

In the last <u>six months</u> how often have you undertaken:

74. Travel outings / vehicle rides (vacations, business trips, visiting family or friends who live outside of your community, etc.):

☐ never
☐ 1-2 times in six months
☐ 3-12 times in six months
☐ at least every two weeks

75. Gardening:

☐ never
☐ light
☐ moderate
☐ all necessary

76. Do-it-yourself household or car maintenance (painting walls, oil change, car tire care, etc.):

☐ never
☐ light (painting, plunging a clogged drain, etc.)
☐ moderate (shovelling snow, installing appliances, etc.)
☐ all necessary

In the last <u>six months</u> how often have you undertaken:

77. Reading books:

☐ none
☐ one in six months
☐ less than one every two weeks
☐ more than one every two weeks

People with MS often feel fatigue. This fatigue is a feeling of physical tiredness and a lack of energy that can stop you from doing the things you want to do.

Place a mark through the line at the point that best describes your fatigue.

81. <u>Your Fatigue Today</u>:
Today, how much does fatigue affect your daily life (the everyday life at home and work) and your relationships?

No effect at   **A very big**
    all   **effect**

82. <u>Your Fatigue Over the Years:</u>
When you think about fatigue in the past, how much did it affect your daily life (the everyday life at home and work) and on your relationships?

No effect at   **A very big**
    all   **effect**

18

Diet: To answer these questions, think about your eating habits in the past year. Indicate how often you eat the following foods. Please include all meals, snacks, and eating out.

83. Lettuce or green leafy salad, with or without other vegetables:

☐ Less than 1 per week
☐ 1 per week
☐ 2-3 times per week
☐ 4-6 times per week
☐ once per day
☐ 2 or more times per day

84. Fruit: include fresh, canned, or frozen but do not include juices:

☐ Less than 1 per week
☐ 1 per week
☐ 2-3 times per week
☐ 4-6 times per week
☐ once per day
☐ 2 or more times per day

85. High fiber cereals or whole grain breads (this includes cereal such as Raisin Bran, Fruit and Fiber, cooked oatmeal and breads which are whole wheat, rye, or pumpernickel).

☐ Less than 1 per week
☐ 1 per week
☐ 2-3 times per week
☐ 4-6 times per week
☐ once per day
☐ 2 or more times per day

86. Are you on a special diet? If so, please describe it below:

_____

_____

_____

<u>Exercise:</u> To answer the following questions, please indicate how many times per week you take part in the following activities <u>for a duration of at least 30 minutes or more</u> at a time.

87. Light exercise (physical activity to an extent where you can still easily talk) Examples:

- light housework (dusting, sweeping, cleaning kitchen counters)
- leisurely walking (walking inside or outside around your house)
- exercises prescribed to you by your physiotherapist
  - ☐ 0 times per week
  - ☐ 1-3 times per week
  - ☐ 4-7 times per week
  - ☐ 8 or more times per week

88. Moderate exercise (physical activity which causes you to feel slightly out of breath) Examples:

- brisk walking
- yoga, Tai-Chi, or moderate exercise classes
- heavy housework (vacuuming, cleaning floors, moving furniture)
  - ☐ 0 times per week
  - ☐ 1-3 times per week
  - ☐ 4-7 times per week
  - ☐ 8 or more times per week

89. Vigorous exercise (physical activity which causes you to breathe rapidly)
Examples:
- weight training and vigorous exercise classes
- swimming
- soccer, basketball, or other sports activities
  - ☐ 0 times per week
  - ☐ 1-3 times per week
  - ☐ 4-7 times per week
  - ☐ 8 or more times per week

90. Exercise in the Past: When you think about your experience over the years, how would you describe your physical activity participation between the ages of 20 and 30?

- ☐ I exercised less than three times per week
- ☐ I exercised regularly about 3 times per week
- ☐ I exercised regularly more than 3 times a week
- ☐ I trained for competitive sports, such as running, hockey, cycling, etc.

91. What are some of your favourite physical activities now?

_____

_____

_____

92. <u>Alcohol:</u> Please indicate how many drinks of the following types of alcohol you consume in an average week. If you do not drink any of a specified type of alcohol below, please place a 0 on the blank:

Wine: _____ drinks (2 – 5 oz. each)

Beer: _____ drinks (10 – 12 oz. each or 1 bottle)

Spirits: _____ drinks (1 – 1.5 oz. each)

93. <u>Smoking:</u> Please indicate your smoking habits below:

94. Do you currently smoke? ☐ Yes ☐ No

95. If yes, how long have you been smoking? _____

96. How many cigarettes do you smoke each day? _____

97. If no, did you ever smoke? ☐ Yes ☐ No

98. If yes, how long ago did you quit? _____

99. How many cigarettes did you smoke each day? _____

100. <u>Life Stress:</u> To answer this question please circle the number which you feel best corresponds to the level of stress in your everyday life:

1	2	3	4	5	6

Not at all stressful   Very Stressful

YOUR THOUGHTS and FEELINGS

Place a mark through the line at the point that best describes how you are presently doing in each area.

101. Concentrating on details:

Not well at all _____ Extremely Well
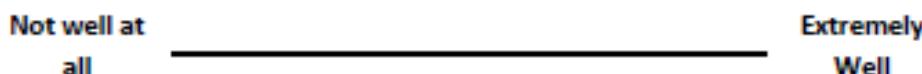
102. Remembering important things

Not well at all _____ Extremely Well
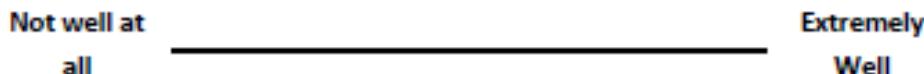
The following are various feelings you may experience in your day-to-day life. Please complete each statement below by checking the best possible answer that applies to you.

103. I feel tense or 'wound up'

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

104. I still enjoy the things I used to enjoy

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

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

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

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

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

107. Worrying thoughts go through my mind:

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

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108. I feel cheerful:

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

109. I can sit at ease and feel relaxed:

- ☐ Definitely
- ☐ Usually
- ☐ Not often
- ☐ Not at all

110. I feel as if I am slowed down:

- ☐ Nearly all the time
- ☐ Very often
- ☐ Sometimes
- ☐ Not at all

111. I get a sort of frightened feeling like 'butterflies' in the stomach:
- ☐ Not at all
- ☐ Occasionally
- ☐ Quite often
- ☐ Very often

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112. I have lost interest in my appearance:

- ☐ Definitely
- ☐ I don't take as much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

113. I feel restless as I have to be on the move:

- ☐ Very much indeed
- ☐ Quite a lot
- ☐ Not very much
- ☐ Not at all

114. I look forward with enjoyment to things:

- ☐ As much as I ever did
- ☐ Rather less than I used to
- ☐ Definitely less than I used to
- ☐ Hardly at all

115. I get sudden feelings of panic:

- ☐ Very often indeed
- ☐ Quite often
- ☐ Not very often
- ☐ Not at all

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

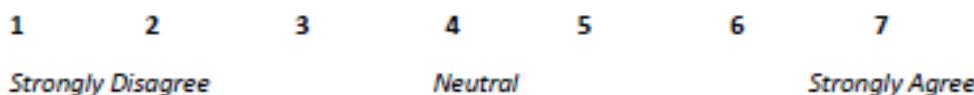*Survey Helpline: 1-866-684-0362*
E-mail Help: mploughm@mun.ca

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Below are some statements with which some people agree and others disagree. Please read each statement and CIRCLE the response most appropriate for you. There is no <u>right</u> or <u>wrong</u> answer.

117. I usually manage one way or another

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   *Neutral*   *Strongly Agree*

118. I feel proud that I have accomplished things in life

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   *Neutral*   *Strongly Agree*

119. I usually take things in stride

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   *Neutral*   *Strongly Agree*
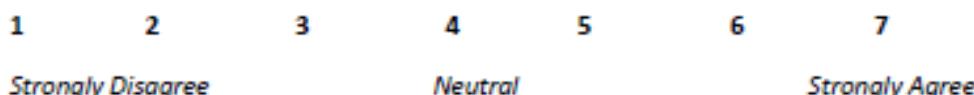
120. I am friends with myself

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
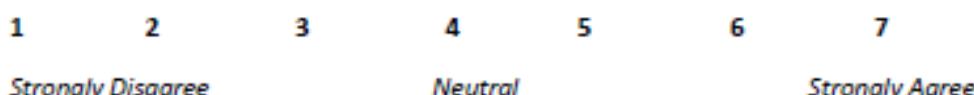
Strongly Disagree   *Neutral*   *Strongly Agree*

121. I feel that I can handle many things at a time

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   *Neutral*   *Strongly Agree*

122. I am determined

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   *Neutral*   *Strongly Agree*

123. I can get through difficult times because I've experienced difficulty before

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   *Neutral*   *Strongly Agree*

124. I have self-discipline

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   *Neutral*   *Strongly Agree*

125. I keep interested in things

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   *Neutral*   *Strongly Agree*

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126. I can usually find something to laugh about

1	2	3	4	5	6	7
Strongly Disagree			Neutral			Strongly Agree

127. My belief in myself gets me through hard times

1	2	3	4	5	6	7
Strongly Disagree			Neutral			Strongly Agree

128. In an emergency, I'm someone people can generally rely on

1	2	3	4	5	6	7
Strongly Disagree			Neutral			Strongly Agree

129. My life has meaning

1	2	3	4	5	6	7
Strongly Disagree			Neutral			Strongly Agree

130. When I'm in a difficult situation, I can usually find my way out of it

1	2	3	4	5	6	7
Strongly Disagree			Neutral			Strongly Agree

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YOUR SOCIAL LIFE

Below are some statements with which some people agree and others disagree. Please read each statement and CIRCLE the response most appropriate for you. There is no <u>right</u> or <u>wrong</u> answer.
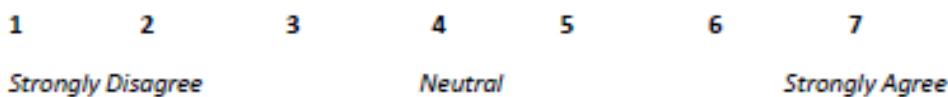
<u>KEY</u>

1 STRONGLY DISAGREE
2 DISAGREE
3 SOMEWHAT DISAGREE
4 NEUTRAL
5 SOMEWHAT AGREE
6 AGREE
7 STRONGLY AGREE

131. There is someone I feel close to who makes me feel secure

1	2	3	4	5	6	7

Strongly Disagree   *Neutral*   *Strongly Agree*

132. I belong to a group in which I feel important

1	2	3	4	5	6	7

Strongly Disagree   *Neutral*   *Strongly Agree*

133. People let me know that I do well at my activities and projects
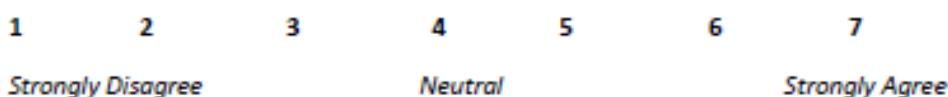
1	2	3	4	5	6	7

Strongly Disagree   *Neutral*   *Strongly Agree*
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134. I have enough contact with the person or people who make me feel special

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   Neutral   Strongly Agree

135. I spend time with others who have the same interests that I do

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   Neutral   Strongly Agree

136. Others let me know that they enjoy working with me (job, committees, projects, volunteering, etc.)

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   Neutral   Strongly Agree

137. There are people who are available if I need help over an extended period of time

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
Strongly Disagree   Neutral   Strongly Agree

138. Among my group of friends we do favours for each other

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Strongly Disagree   Neutral   Strongly Agree

139. I have the opportunity to encourage others to develop their interests and skills

1	2	3	4	5	6	7

Strongly Disagree   *Neutral*   *Strongly Agree*

140. I have relatives or friends that will help me out even if I can't pay them back

1	2	3	4	5	6	7

Strongly Disagree   *Neutral*   *Strongly Agree*

141. When I am upset, there is someone I can be with who lets me be myself

1	2	3	4	5	6	7

Strongly Disagree   *Neutral*   *Strongly Agree*

142. I know that others appreciate me as a person

1	2	3	4	5	6	7

Strongly Disagree   *Neutral*   *Strongly Agree*

143. There is someone who loves and cares about me

1	2	3	4	5	6	7

Strongly Disagree   *Neutral*   *Strongly Agree*

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144. I have people to share social events and fun activities with

1	2	3	4	5	6	7

Strongly Disagree   *Neutral*   *Strongly Agree*

145. I have a sense of being needed by another person

1	2	3	4	5	6	7

Strongly Disagree   *Neutral*   *Strongly Agree*

YOUR OPINIONS

146. From your point of view, what are the most important things that help you live long and healthy with MS?

_____

_____

_____

_____

_____

147. If you would like to make any final comments about this questionnaire or the study itself, please record them in the space provided below. If you need more space for writing, feel free to attach an additional piece of paper:

_____

_____

_____

_____

_____

This is the end of the survey booklet! Please return this survey in the postage-paid envelope provided. Thank you very much for your time and participation!!!

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