

FACTORS ASSOCIATED WITH GENERAL HEALTH AND MENTAL HEALTH IN  
PEOPLE LIVING WITH CHRONIC NEUROLOGICAL CONDITIONS

by

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## **ABSTRACT**

The purpose of this study was to explore the factors associated with self-reported general health (SRH) and mental health (SRMH) for adults living in Canada with chronic neurological conditions. A secondary analysis of data from a sample of participants drawn from the Living with the Everyday Impact of a Neurological Condition (LINC) study was conducted.

Independent variables were organized according to the Person Environment Occupation (PEO) Model. Linear regression analysis identified factors associated with SRH and SRMH. SRH was most influenced by fatigue and self-efficacy, while SRMH was most influenced by depression and self-efficacy. SRH was negatively associated with fatigue and positively associated with self-efficacy. SRMH was negatively associated with depression and positively associated with self-efficacy. Depression, fatigue and self-efficacy are critical clinical factors that need to be addressed to maximize health for this population.

## LIST OF ABBREVIATIONS USED

DALYs	Disability life adjusted years
E	Environment
LINC	Living with the Everyday Impact of a Neurological Condition
O	Occupation
OLS	Ordinary Least Squares
P	Person
PEO	Person Environment Occupation
SRH	Self-rated health
SRMH	Self-rated mental health
TBI	Traumatic Brain Injury
WHO	World Health Organization

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## **CHAPTER 1 INTRODUCTION**

### **1.1 PROJECT OUTLINE**

The aim of this research project was to improve knowledge of the factors associated with self-reported general health (SRH) and mental health (SRMH) of adults living in Canada with a chronic neurological condition. Knowledge of these factors may enable healthcare professionals to meet patient needs and improve SRH and SRMH. Chapter one offers an introduction to the research project and outlines the need for enhancing our understanding of the factors that influence SRH and SRMH for this population. Chapter two reviews and summarizes the current literature about the Person Environment Occupation (PEO) Model, SRH, SRMH, and the PEO factors associated with SRH. Chapter three is a manuscript on the factors associated with SRH and SRMH in adults living with chronic neurological conditions, planned for submission. Chapter four includes a discussion of an ordinal regression analysis completed as an additional analysis to address the research aim. Chapter five provides a short conclusion.

### **1.2 SCOPE OF NEED**

Neurological conditions are a worldwide cause of death and disability, negatively impacting self-reported general health (SRH) and mental health (SRMH) for individuals with those conditions (CIHI, 2007; Bray et al., 2014; WHO, 2006). In 2006, neurological conditions were documented to affect roughly a billion people globally, which accounted for 6.3% of the total global burden of disease (WHO, 2006). A decade later, neurological conditions were responsible for 276 million disability life adjusted years (DALYs) or 11.6% globally for all diseases and were the underlying cause in 16.5% of total global deaths (Feigin et al., 2017).



Based on these numbers, globally, neurological conditions are the second leading cause of death and the leading cause of disability (Carroll, 2019).

The burden of neurological conditions in Canada is consistent with the global impact. In 2007, neurological conditions were responsible for 10.6% of total disability adjusted life years (DALYs) for illness in Canada (Tator, et al., 2007). By 2031 models predict that more Canadians living with neurological conditions will experience severe disability and, depending on the condition, will lose 14 to 41 equivalent years of life living in full health (PHAC, 2014). There are also significant economic costs. In 2008, neurological conditions were estimated to cost roughly \$192.8 billion Canadian dollars a year, which was a 13.8% increase from 2005 to 2008 (PHAC, 2014). These figures consider direct and indirect costs related to the burden of these conditions. Direct costs include expenditures related to hospital care, physician care, and prescription medication. Examples of indirect costs are lost productivity related to the employment of the individual as well as the informal caregiver as they cut back on employment to care for the individual. Informal caregivers experience significant emotional burden. Caregivers for individuals living with a neurological condition report twice the level of distress, or 28%, as compared to those caring for individuals without a neurological condition (Turcotte, 2013).

As evident from the data, the burden of neurological conditions is significant and continues to increase. While age-standardized incidence, mortality, and prevalence rates of many neurological disorders declined for the past three decades, the absolute number of people dying or remaining disabled from neurological disorders over the past quarter century has been increasing (Feigin et al., 2017). Moreover, people are living longer with these conditions (Gaskin et al., 2017). This is notable given that Canadians living with a neurological condition report fair

to poor levels of SRH roughly three times more than the general population (Gaskin et al., 2017; PHAC, 2014; WHO, 2006).

As a subjective evaluation, SRH indicates a person's overall perception of their health and is more sensitive to change in monitoring total health than more objective measures, which may not capture the full impact of a disease (Bonner et al., 2017; Cella et al., 2012; Idler & Benyamini, 1997; Miilunpalo et al., 1997). Individuals living with neurological condition also report lower SRMH. Compared to the general population, a greater proportion of Canadians with a neurological condition report high levels of stress or a diagnosis of a mood or anxiety disorder (Bray & Huggett, 2016).

As populations are growing and aging, and neurological conditions increase with age, governments will encounter mounting pressure for treatment, rehabilitation, and support services for people with neurological conditions (Feigin, 2016). In addition to the consequences already mentioned, individuals living with these conditions can be impacted by impairments related to mobility, upper extremity function, and cognition as well as greater levels of stigma (PHAC, 2014). Because neurological conditions are, for the most part, managed, not cured, it is crucial to identify those factors that directly or indirectly contribute to better SRH. SRH has been identified as a predictor of mortality, physical functioning, health services utilization and provides insight into how individuals perceive the impact of disease on their life (Bonner, et al., 2017, Soh et al., 2012). Addressing variables related to SRH will enable rehabilitation professionals and healthcare systems to direct resources towards factors that have the greatest potential to enhance the lives of those living with neurological conditions and reduce the associated burden.

To achieve this objective, new treatments and rehabilitation approaches are needed to address the diverse impacts of neurological conditions (Bray et al., 2014). There is also

increasing recognition that health professionals should look beyond the disease, impairments, and associated deficits (Turner et al., 2009). Service providers and policymakers have advocated the need for models of care that shift the emphasis from diagnosis to functional requirements to meet patient needs and improve SRH (Bray & Huggett, 2016; Jaglal et al., 2014). This approach to understanding rehabilitation with neurological conditions embraces the concept that living with a chronic condition goes beyond knowledge of disease mechanisms (Josman et al., 2020). Compared to people of the same relative age, more Canadians with a neurological condition with “poor” or “fair” SRH report limitations of usual activities or are permanently unable to work (Bray & Huggett, 2016).

The concept of participation in everyday occupations has emerged as a key concern in rehabilitation theory, clinical practice (McLean et al., 2014) and is considered an important rehabilitation outcome (WHO, 2002). Better SRH and SRMH have been reported by individuals living with a chronic neurological condition with fewer restrictions with participation in daily activities (Andelic et al., 2010). Participation in everyday occupations represents an important rehabilitation outcome because it embodies the extent to which a person resumes an active role in valued personal and social pursuits (Stiers et al., 2012). Theoretically, occupational therapists believe that a relationship exists between occupational performance and SRH (Law et al., 1998; Wilcock, 1993). Occupational performance is defined as the subjective evaluation of an individual’s level of satisfaction and ability to perform daily occupations (Law et al., 1996). By engaging in occupation, an individual has the potential to satisfy needs related to meaning, purpose and social connectedness thereby improving SRH (Hammell, 2004).

The Person Environment Occupation (PEO) Model is a conceptual framework to understand the complex interrelationship among factors that contribute to occupational

performance (Law et al., 1996). This model provides a framework to understand how transactions between person, environment, and occupation factors combine to shape occupational performance.

Although participation in daily occupations has been positively associated with SRH within cohorts of individuals living with chronic neurological conditions (Forslund et al., 2013; Hartman-Maeir et al, 2007; Mayo et al., 2002; Warner et al., 2018; Winter et al., 2011), it is not clear if this finding is consistent across all neurological conditions. Most research on neurological conditions to date is diagnosis-specific (Auduly et al., 2014). It is also unclear how other contextual factors influence SRH and SRMH across neurological conditions. The assortment of factors that affect those living with a chronic neurological condition, such as physical and cognitive impairment, depression, and environmental variables individualize the experience (Kalpinski et al., 2013; McLean et al., 2014; O'Reilly et al., 2018). Understanding the association of occupational performance and confounding variables with SRH and SRMH across neurological conditions would enable healthcare professionals to design effective rehabilitation programs to meet patient needs and improve SRH and SRMH.

The aim of this study was, therefore, using the PEO Model as a guide, to determine which PEO factors are associated with SRH and SRMH for adults living in Canada with a chronic neurological condition. The findings from this study can provide direction to rehabilitation professionals working to improve SRH and SRMH in adults living with a chronic neurological condition.

## CHAPTER 2 LITERATURE REVIEW

### 2.1 DESCRIPTION OF PEO MODEL

The PEO Model was developed as a conceptual framework to describe occupational performance, conceptualized as the relationship between three interdependent elements: the person (P), the environment (E), and the occupation (O) (Law et al., 1996). According to Law et al. (1996), the person is an individual with physical, cognitive, and affective qualities consequently having their own unique abilities, skills, identities, experiences, and motivations. The environment includes the social-economic, cultural, physical and institutional contexts of each individual. Occupation refers to clusters of activities with inherent meaning that an individual participates or engages in to meet his or her needs or for a specific purpose.

The primary assumption of the PEO Model is that the three elements interact to either support or diminish occupational performance (Law, Steinweinder & Leclair, 1998; Law et al., 1996). Occupational performance is defined as the subjective evaluation of an individual's level of satisfaction and ability to perform daily occupations (Law et al., 1996). Meaningful or successful occupational performance is the outcome of an interaction in which the person is appropriately matched to the occupational and environmental supports and demands (Schwartzman et al., 2006). In contrast, a lack of congruence, or poor fit, between person, environment, and occupation factors decreases occupational performance. Therefore, this model provides a framework to understand and evaluate areas that affect a person's occupational performance and an intervention framework to help improve a person's occupational performance by improving the congruence of the three domains.

## 2.2 APPRAISAL OF PEO MODEL

To date, research using the PEO Model is limited in volume and scope. Most of the published literature consists of using the PEO Model as an analytical tool or theoretical model to guide practice (i.e. case study). One of the early, applied papers on the PEO Model was by Strong et al. (1999). The authors provided an overview of the model and offered several scenarios to support the application of the model in practice. While the paper did not empirically test the underlying assumptions of the model, it highlighted the flexibility of the model to capture the potential variations in P, E, and O elements (i.e., across the lifespan, different environments, the changing person). As stated by the authors, “a strength of the PEO Model is that it enables therapists to consider the complexities of human functioning and experience in the day-to-day realities of clients’ lives and therapist’s practices.” (p. 131).

Other research has supported the work by Strong and coauthors asserting the flexibility of the PEO Model. Using two different research designs, Vaughan (2020) and Vrkljan (2010) both chose the PEO Model to explore the complex factors and relationships between P, E, and O elements. Vaughan (2020) explicitly chooses the PEO Model over other models because of its ability to see how occupational performance is shaped by the interaction between the person, the environment, and the occupation.

Vaughan (2020) qualitatively explored the strengths and weaknesses associated with the design of a library space. Occupational performance was measured by staff satisfaction and efficiency. Using a series of observations and interviews, Vaughan identified those factors associated with the environmental design of the space, specifically at the service point. The service point is the area where library staff interacts with its users. Factors identified through the PEO Model included addressing undesirable behaviors at the service point (P), addressing the

size, visual weight, and feel of the service point (E), and making changes to access, circulation, and reference services at the service point (O). Overall, the study demonstrated the flexibility of the model and that occupational performance is shaped by the interaction of the PEO factors.

Vrkljan (2010) used the model within a mixed-methods design to explore technology use in older adulthood. The author first explored how previous experiences with technology influenced the interaction and performance of twenty-two older, married couples when using new technology. Then the PEO model was used to frame how key transactions between P, E, and O factors might inform clinical decision making when prescribing new technology to older clients. Specifically, Vrkljan explored the relationships between P-O, O-E, and P-E factors that influenced technology use through two couples. Vrkljan found that technology use was dependent on several factors. For example, how and when technology was used was dependent on an individual's previous experience with technology, the opportunities afforded based on the social environment, and the support of a partner. This study demonstrated that the PEO Model may be used as a framework to explore client factors with a diverse range of needs. A limitation of this study was that occupational performance was specifically restricted to technology use.

Like Vrkljan, Ambrose et al. (2020) used the PEO Model as an evaluative lens to summarize the P, E, and O transactions in studies examining joint attention span. As a scoping review of literature related to joint attention span in children with Autism Spectrum Disorder, the authors focused on how joint attention changed as a result of transactions between P-E, P-O, and E-O. To achieve this outcome, the authors used the Arksey and O'Malley five-step method to guide the review. Inclusion criteria for study selection were (a) English language; (b) publication in a peer-reviewed journal between 2008 and August 2019; (c) joint attention performance as an outcome of the study; (d) joint attention performance of autism spectrum disorder group

compared to a typically developing group; and a mean age of participants between 6 and 12 years. Following the study selection, the authors mapped the transacting components onto each of the final six studies. Subsequently, the authors identified the transactions occurring within the protocols of each of the retained studies. The P–E transactions identified to what extent the way participants had to engage with joint attention cueing influenced how the cues were delivered. The P–O transactions identified to what extent the way participants were asked to engage joint attention cueing influenced how joint attention was demonstrated. Finally, The E–O transactions identified to what extent the way joint attention cues were delivered influenced how joint attention was exhibited. Although only six studies were included, the authors found evidence that relationships exist between P, E, and O elements and the outcome of interest, joint attention.

A weakness of this review is the lack of occupational performance measure as an outcome. Joint attention is a factor within the person that contributes to occupational performance as opposed to an end in and of itself. On the other hand, as the literature was extracted from papers outside of typical occupational therapy literature, the authors concluded that the PEO Model represents a systematic model for organizing literature outside of occupational therapy. However, the authors also state that further appraisal is required.

While the flexibility of the PEO Model is evident based on existing literature and generally considered a strength of the model, it is not without its shortcomings. Maclean et al. (2012) used the framework to explore practice in an acute care setting with interesting results. Using a qualitative design, the authors had two objectives; explore the value of using the PEO Model in an acute care setting and discover the limitations of the PEO Model in practice. Like the previously mentioned research, the authors concluded that the PEO Model provides flexibility and is a good framework for organizing complex issues in practice. However, in



contrast to other research, the authors found that while some participants found the model too simple, others found it too complex. In this instance, the authors suggested that the open nature or simplicity of the model may lack the necessary detail for some therapists. In other words, the challenge of gathering and appraising the different factors may be an issue, as the model does not make this clear (Duncan, 2011). This may be a challenge to therapists depending on experience or clinical background. In contrast, as other research has suggested, the broad mandate may be a strength in research. Additionally, like the conclusion of Ambrose et al. (2020), Maclean et al. (2012) also identified that, unlike other occupational therapy models, the PEO offers succinct language, which would be beneficial when explaining factors across different practice settings and professions.

One of the only studies testing the underlying assumption of the PEO model and the relationship between the P, E, and O elements and occupational performance, is a case study by Fathipour-Azar and Shirmard (2018) in cardiac rehabilitation. According to the authors, people with heart disease can have complex problems including restrictions in daily occupations and impairments related to affect, cognition and physical factors. These problems also impact and are impacted by the individual's environment. The authors felt that the PEO Model represented an appropriate model to reflect on the complex nature of occupational performance. Based on the PEO model the authors used a three-step approach to support occupational performance. The authors identified occupational performance strengths and problems in step one. In step two, the person, occupation, and environmental factors were evaluated. The third step included a plan for intervention and evaluation of the outcomes. The intervention addressed components of each of the PEO factors. The participant and family received education related to her condition, occupations were modified, and aerobic activity was initiated. The participant received three

sessions a week over a 6-month period. Using the Canadian Occupational Performance Measure as an outcome measure and the PEO Model as a framework, the client reported greater ability and satisfaction with daily activities and greater quality of life. Specifically, the client reported higher ability and satisfaction with traveling, carrying objects, and doing handmade crafts. Her family supported these assertions. A strength of this study is the application of the PEO model to a complex condition. As a case study, the limitation of this study is the inability to generalize the findings to a larger sample, which the authors note. The next step is to apply the PEO Model to a larger study design.

The PEO model offers a flexible framework to view the complex and interdependent relationships that exist between factors that contribute to occupational performance. Several studies demonstrated the value of the PEO model as an evaluative lens to examine PEO transactions. The research also demonstrated the applicability of the PEO model to understand the variety of factors associated with complex cases and settings. The model also offered a means to communicate these findings across different bodies of literature and professions. In summary, based on the evidence, the PEO model represented an appropriate framework to support the aim of this project.

## **2.3 INTRODUCTION TO SELF-REPORTED HEALTH**

Widely used in research, SRH is a subjective assessment of current health status as perceived by the individual and is considered a total measure of a person's health status and its functional consequences (Roysamb et al., 2003; Wu et al., 2013). SRH has been correlated with and predictive of health outcomes including healthcare utilization (Kaleta al., 2006; Miilunpalo

et al., 1997), morbidity (Dominick et al., 2002; Ferraro et al., 2000), and mortality (Benyamini & Idler, 1999; Idler & Benyamini, 1997). It has demonstrated greater sensitivity in monitoring overall health above and beyond objective measures (Bonner et al., 2017; Cella et al., 2012; Idler & Benyamini, 1997; Miilunpalo et al., 1997).

As a global measure of health, SRH represents an overall assessment of health perception including physical, psychological, and social elements via self-appraisal (Hardy et al., 2014). Physical elements, or objective health measures, associated with SRH in the literature include functional level (Idler et al., 2000; Idler & Kasl, 1995), recovery from illness (Wilcox et al., 1996), and health risk factors such as resting heart rate, blood pressure, cholesterol, and body mass index (Lorem et al., 2017). The results of these associations are generally consistent; disease severity, functional decline and symptom burden are associated with poor SRH (Shields & Shoosharti, 2001).

Psychological, cognitive, and affective elements also play a role in health perception. Cognitive impairment (Lawson et al., 2014; Shrag et al., 2000), anxiety and associated symptoms (Berrigan et al., 2016), and depression and associated symptoms (Johnson et al., 2004; Kadastick-Eerme et al., 2015) have all been negatively associated with SRH.

As the subjective evaluation of one's health is contextualized in a socio-economic framework, social factors represent another element in the self-appraisal of one's health. Social factors associated with SRH include income (Janzen et al., 2013), social support (Yamout et al., 2013; Winter et al., 2011), and stigma (Gershon et al., 2011). In general, income and social support are positively associated with SRH, whereas stigma is negatively associated with SRH.

## **2.4 OBJECTIVE AND SUBJECTIVE COMPONENTS CONTRIBUTE TO SELF-REPORTED HEALTH**

Individuals use additional information, beyond objective health indicators, to determine SRH (Bauhoff, 2011). Over four decades ago, Tissue (1972) stated that SRH “represents a summary statement about the way in which numerous aspects of health, both subjective and objective, are combined within the perceptual framework of the individual respondent” (p 93). Objective health measures, sometimes referred to as “actual” health indicators such as blood pressure, cholesterol, and obesity, provide direct evidence of health status of individuals, including previous and current diseases and clinical parameters (Wu et al., 2013). It also includes knowledge of those conditions conveyed by health professionals (Jylhä, 2009).

Subjective health is how people perceive their health. It represents the difference between objective measures and the individual’s perception (Altman et al., 2016). Researchers have identified several explanations about how people form these perceptions of SRH. One, an individual’s knowledge of their health condition is used in constructing SRH (Falconer & Quesnel-Vallée, 2017). Hence, objective measures are a factor in how they assess their health. Two, individuals also compare themselves to others with the same group of health conditions (Altman et al., 2016). Third, SRH is influenced by an individual’s lived experience (Bostan et al., 2014). According to Bostan et al. (2014), the lived experience refers to the extent to which people can perform actions and tasks, the person’s level of adaptability including adaptive aids, their attitudes towards the health condition, and their emotions or feelings. Consequently, individuals living with chronic disease can rate their SRH in favorable terms despite the presence of chronic illness and disability (Cott et al., 1999).

## **2.5 HOW INDIVIDUALS DETERMINE THEIR RATINGS OF SELF-REPORTED HEALTH**

How an individual formulates their rating of SRH is a topic of much discussion. SRH is thought to be produced in an integrated cognitive process reflective of biological, psychological, and socioeconomic factors (Lore et al., 2017; Miilunpalo et al., 1997). Although a cognitive process, the perception of SRH is not entirely conscious. Jylhä, (2009) suggested that physiological states, which contribute to the determination of SRH, are conveyed as bodily sensations and that these biological messages are perceived by the individual as sensations, feelings, and emotions. Damasio (1996) alluded, through the somatic marker hypothesis, that these sensations are integrated with available knowledge and individual experience through higher cognitive functions to reach a decision. This would explain how objective health information (Hardy et al., 2014), previous and present health experiences (Jylha, 2009), beliefs such as self-efficacy (Stephens et al., 2016) and culture (Krause & Jay, 1994; Roudijk et al., 2017; Zajacova & Beam Dowd, 2011) are integrated to formulate SRH. This integrative process also offers some explanation as to how SRH simultaneously displays both enduring and spontaneous features throughout changing health conditions (Perruccio et al., 2010). Thus, individuals formulate their health ratings by processing emotional states, available medical information and its significance, as well as everyday functioning (Hardy et al., 2014).

## **2.6 MEASUREMENT OF SELF-REPORTED HEALTH**

Instruments to measure SRH vary greatly and depend on the purpose of measurement (Garbarski, 2016). Measures include surveys and interviews; are disease-specific or generic; and

range from single item to multi-dimensional tools (Cousins, 1997; Heffernan & Jenkinson, 2005).

Generic questionnaires are designed for broad application across types and severities of disease, across demographic and cultural groups, and to assess outcomes across different medical treatments or health interventions (Garbarski, 2016). The classic, single question with a five-point Likert-type response scale, rating health from excellent to poor, is a commonly used generic measure of SRH (Clarke & Ryan, 2006; Gallagher et al., 2016). In comparison to the single-item question, the short form-36 (SF-36) is a widely used, multi-item, generic assessment of SRH (Lins & Carvalho, 2016). Whereas single-item measures are broad summary ratings of diverse aspects of an individual's health, the multi-item measure helps identify differences by area or domain (Bowling, 2005).

In contrast to generic measures, condition-specific measures of SRH frequently focus on aspects of a disease that are not covered by generic measurements (Hefferan & Jenkinson, 2005). Condition-specific measures can capture matters of concern related to specific health conditions (Lapin, 2020). However, different instruments tend to be used across diverse neurologic conditions, making cross-disease evaluations of SRH difficult (Heffernan & Jenkinson, 2005). This hinders cross-study comparisons of the variables that may influence SRH, comparative disease burden, benefits of different treatments, or other factors (Cella et al., 2012). Consequently, generic instruments enable measurement across diseases, disorders and, in the case of some tools, enable comparisons with the general population (Guyatt et al., 1993; Schrag et al., 2000).

In addition to generic and condition-specific instruments, SRH measures are either non-preference or preference-based (Ojelabi et al., 2019). Preference-based tools measure how

desirable or undesirable a health state is from the perspective of the population. Non-preference-based measures are person-specific, considering all the factors that influence SRH (Leung et al., 2007; Ojelabi et al., 2019). Whereas both measures aim to measure SRH or change in SRH perceived by individuals, the purpose of a preference-based measure is to place a value on health states by using a scoring algorithm that incorporates preferences that reflect a valuing of different health states (Abel et al., 2017; Brazier & Deverill, 1999).

The choice of instrument depends on the desired outcome or why SRH is being measured. For example, preference-based measures may be useful to evaluate outcomes such as quality-adjusted life years (Lapin, 2020). Alternatively, non-preference-based measures may be helpful to elicit communication from the client or to understand the client's perspective of health (Lapin, 2020). An example of an easy-to-administer, non-preference-based measure is the previously mentioned single question with a five-point Likert-type response scale (Gallagher et al., 2016). Examples of preference-based measures include the Health Utilities Index—Mark 3 (HUI3) (Furlong et al., 2001) and the six-dimensional health state short form (SF-6D) (Walters & Brazier, 2003). In summary, both non-preference and preference-based measures provide an assessment of health status but from two different perspectives. The choice of instrument depends on the desired outcome.

## **2.7 THE SINGLE ITEM, FIVE POINT SCALE AS A MEASURE OF SELF REPORTED GENERAL HEALTH**

While many instruments are available to evaluate SRH of individuals living with a chronic, neurological condition, there is no agreement on a single, most appropriate measure

(Cella et al., 2012; Garbarski, 2016). In order to make suitable conclusions regarding SRH data, instruments must be appropriate for the population and show valid and reliable measurement properties (Lapin, 2020). The single item, five-point scale meets these characteristics and represents an appropriate generic, non-preference-based measure to evaluate SRH in individuals across a broad range of neurological conditions.

The single-item SRH question was first used as an alternative for clinical assessment of illness in survey methods research. It is a frequently used, easy-to-administer measure of general health (Ahmad et al., 2014; Clarke & Ryan, 2006; Strawbridge and Wallhagen, 1999). In a systematic review to evaluate the determinants used in models of SRH, of the 56 studies included in the final review, 91% relied on some version of the single-item question (Mantzavinis et al., 2005). In a recent systematic review to understand the relationship between SRH and stroke, roughly 31 of the 51 included studies used some version of the single-item question (de Freitas Araújo et al., 2019). Based on the literature, it has a significant pattern of use in measuring SRH in both general and neurological populations.

While the exact wording and response options vary, the single-item SRH question typically asks respondents to choose a response that best describes their general health on a four or five-point scale (Jylhä, 2009). Two frequently used five-point scales provide response scales ranging from ‘very good’ to ‘very poor’, or from ‘excellent’ to ‘poor’ with the different versions representing parallel assessments of health (Jürges et al., 2008).

Garbarski et al. (2015) suggested that the response order of the questions may influence the outcome. In their study of 2,696 subjects, the authors reported higher SRH and a lower proportion of “fair” to “poor” SRH when response rates are ordered from “excellent” to “poor” (Garbarski et al., 2015). They found similar results in a replication study (Garbarski et al., 2016).



On the other hand, in their sample of 5470, Eriksson et al. (2001) found that, though the correlations were at slightly different levels for the SRH measures, there were no differences in the patterns of associations with the independent variables and any differences produced using different scales were marginal. In summary, calculating health levels based on different measurements of SRH are not directly comparable and require rescaling of items but the relationships that exist between the SRH and the independent measures across the measures are consistent (Jürges et al., 2008). Thus, the SRH single-item question offers reliability, clinical significance, and the ability to generalize findings using the same tool.

The single-item SRH measure has demonstrated reliability (Lundberg & Manderbacka, 1996), validity, feasibility, and inclusivity for individual health and population-based studies (Jylhä, 2009; Orpana et al., 2017; Rampage-Morin, Shields & Martel, 2010), and persons living with chronic neurological conditions (de Freitas Araújo et al., 2019; Yang, et al., 2017), including those living with cognitive impairment (Baumstarck et al., 2013). The single-item measure, however, is limited to within the same culture as it lacks cross-cultural comparison (Jylhä et al., 1998). Through the cognitive process, previously described, individuals in different cultures and contexts ascribe different meanings to health and health conditions.

One complaint of the single-item SRH measure is the potential ambiguity associated with what is being measured. As the self-assessment of SRH is subjective in nature, researchers cannot standardize or even know which dimensions of health the respondent really is assessing or what criteria he or she is using (Jylhä et al., 1998). However, on the contrary, given its somewhat abstract nature, ratings on an ambiguous measure like the SRH single-item measure might reflect health awareness not captured by the specific health indicators but nonetheless relevant to a rating of global health (Hardy et al., 2014).

## **2.8 THE SINGLE ITEM, FIVE POINT MEASURE OF SELF-REPORTED MENTAL HEALTH**

While SRH has been shown to reflect physical and psychological dimensions, researchers have also suggested a need for a specific self-rated measure for mental health using a similar single-item question (Mawani & Gilmour, 2010). Like SRH, SRMH measures an individual's perception of their overall mental health using the same previously discussed single question rated on a five-point scale (Ahmad et al., 2014). It is defined as a person's state of psychological well-being as perceived by that person (Mawani & Gilmour, 2010).

Compared with the abundance of research on the correlates of SRH, the body of research on SRMH is much smaller. Individual studies report significant associations between SRMH and the presence of mental disorders (Hoff et al., 1997), greater limitations in activity and role functioning and the corresponding need for assistance (Zuvekas & Fleishman, 2008), greater healthcare utilization (Nabalamba & Millar, 2007) and a lower level of satisfaction with healthcare services (Ahmad et al., 2014). Ahmad et al., (2014) conducted a scoping study of published studies that either used or analyzed the single-item SRMH with the goal of gaining a better understanding of how single item SRMH is used in research and how it correlates with other measures and health outcomes. The researchers found that SRMH was negatively associated with SRH and physical health problems.

SRMH has demonstrated significant associations with several other measures of mental illness. In a 2010 validation study in the Canadian population, researchers reported significant associations between all mental morbidity measures, which included the self-reported diagnosis

of mental disorders and level of stress (Mawani & Gilmour, 2010). The authors concluded that SRMH is a useful indicator for monitoring general mental health. Admed et al. (2014) also noted moderate correlations between SRMH and other mental health scales.

However, the single-item SRMH measure is not without limitations. SRMH cannot be used to examine trends, explore etiology, predict the need for treatment, or determine if those who need treatment are receiving it (Mawani & Gilmour, 2010). It has, however, been shown to predict the future risk of depression (Hoff et al., 1997). Like the ambiguous nature of the single-item SRH measure, SRMH may be accounting for factors outside the scope of mental health scales. Based on current literature it is unclear what these other factors are (Zuvekas & Fleishman, 2008). Still, SRMH captures a perception of an individual's mental health (Ahmed et al., 2014).

## **2.9 SELF REPORTED HEALTH AND THE PEO FACTORS RELATED TO NEUROLOGICAL CONDITIONS**

The PEO Model does not explicitly identify health as an outcome. The PEO model implies that each of the P, E, and O variables may enhance or diminish occupational performance. However, an underlying premise of occupation is that a relationship exists between occupation and health (Law et al., 1998; Wilcock, 1993). Wilcock (2007) has suggested that health occurs through engagement in occupation. Similarly, the American Occupational Therapy Association (2008) recommends the promotion of health through occupation. Based on this it seems reasonable to assume that successful occupational performance, as a product of the P, E, and O factors, would demonstrate a positive relationship with health. However, it is also possible

that other associated P and E factors may influence SRH and SRMH. No research exists examining these relationships across those living with chronic neurological conditions. The following sections will explore the existing evidence between each of the individual PEO factors and SRH in those living with chronic neurological conditions.

## **2.10 PERSON FACTORS ASSOCIATED WITH SELF-REPORTED HEALTH**

Neurological conditions result in numerous physical (Derosiers et al., 2006; Morris, van Wijck, Joice, Donaghy, 2012; Sangha et a., 2015; Winter et al., 2011) and cognitive impairments (Foster & Hershey, 2010; Lawson et al., 2014; Shrag et al., 2000) and are often associated with affective related symptoms such as depressive (Ho et al., 2009; Kadastick-Eerme et al., 2015; Patten et al., 2003; Tate et al., 2015) and anxiety (Berrigan et al., 2016; Fan et al., 2016; Johnson et al., 2004). The degree to which these factors influence SRH varies across conditions and other person-level factors such as age (Alcañiz & Solé-Auró, 2018; Forslund et al., 2013), comorbidity (Berrigan et al., 2016; Gilmour et al, 2018), and self-efficacy (Robinson-Smith et al., 2000; Shnek et al., 1997; Stephens et al., 2016). The following section will describe the relationships between SRH and each of the physical, cognitive and affective components in individuals living with chronic neurological conditions.

### **2.10.1 PHYSICAL FACTORS ASSOCIATED WITH SELF-REPORTED HEALTH**

Person-factors related to physical symptoms and impairments are common within and across neurological conditions. Physical symptoms and impairments known to be negatively associated with SRH are fatigue (Amato et al., 2001), sleep disturbance (Sankari et al., 2019),

upper extremity function (Morris et al., 2012), and lower extremity function (Derosiers et al., 2006; Sangha et al., 2015). In addition to physical symptoms, other person-level factors such as age (Alcañiz & Solé-Auró, 2018; Forslund et al., 2013) and comorbidity (Berrigan et al., 2016; Gilmour et al., 2018) have demonstrated a relationship with SRH in individuals living with a chronic neurological condition.

Increasing levels of fatigue are directly and indirectly associated with lower SRH. Numerous studies have demonstrated that fatigue is negatively associated with SRH (Amato et al., 2001; Cantor et al., 2008; Fernández-Muñoz., 2018; Soh et al., 2011). Fatigue is also negatively associated with physical function, affect, and ability to perform daily activities, all of which are also associated with poorer SRH (Berrigan et al., 2016; Herlofson & Larsen, 2003). Indirectly, in a sample of 949 adults with MS, using regression and cross-section path analysis, Berrigan et al. (2016) found that fatigue compounded the negative influence of comorbidity on SRH.

Fatigue has also been negatively associated with depression. While both factors are associated with SRH, it has been proposed that the relationship between fatigue and depression may be bidirectional with each contributing to each other (Fernández-Muñoz., 2018). However, other authors have failed to note this bidirectional relationship (Šabanagić-Hajrić et al., 2015). Fatigue may also result from an undesirable effect of treatment, or a symptom of depression, or secondary to sleep disturbance (Feinstein et al., 2014).

Sleep disorders are more common in individuals living with a neurological condition than in the general population. Sleep disorders are negatively associated with SRH and participation in daily activities (Lobentanz et al., 2004; Martinez-Martin et al., 2011; Penner & Paul, 2017; Sankari et al., 2019). Sleep disturbance is associated with a higher risk of comorbidity related to

cardiovascular disease, metabolic disorders, and mood disorders (Giannoccaro et al., 2013). Visser et al. (2008) reported that sleep disturbance was negatively associated with the ability to complete activities of daily living. It is possible that sleep has an indirect effect on SRH by both limiting daily activities and coping abilities (Karatepe et al., 2011).

Physical impairments related to motor function, including the upper extremity and lower extremity, are common consequences of neurological conditions. Roughly 50% of Canadians with neurological conditions report mobility limitations and impaired upper extremity function with each exerting its own influence on SRH (Bray et al., 2014). Winter et al. (2011) used the EuroQoL-5D, a generic health measure, to measure SRH in 70 outpatients living with Parkinson's Disease. The researchers reported that impairments in motor function and disease severity were negatively associated with SRH.

A 2010 study of 528 stroke patients, one-year post stroke, found that the strongest predictor of lower SRH was a lack of motor recovery of the upper and lower extremities (Franceschini et al., 2010). Upper limb function and lower limb function were assessed using the Upper Limb Motricity Index and Lower Limb Motricity Index, developed for measuring motor impairment of individuals living with stroke. Both measures are scored on three motions of the upper extremity and the lower extremity, respectively, from 0 to 33, with 0 denoting non-movement and 33 representing normal strength. The three scores are totaled resulting in a final score of 0 to 99. Using the single-item question of SRH, the researchers reported that both lower extremity and upper extremity impairment were negatively associated with SRH. The researchers also found that the presence of a catheter was negatively associated with SRH. Together with the upper and lower extremity measures, these findings could suggest that those experiencing lower SRH had poor recovery from the stroke one-year post. A limitation reported by the authors was

selection bias. Patients with more severe impairment were excluded from the study due to cognitive and communication deficits. Given that excluded patients had greater severity it is unlikely that the negative association would change the outcome.

Despite the apparently strong negative correlations between SRH and physical impairments, it is not clear if this is a result of a loss of bodily function or if there is an indirect effect through the loss of autonomy or inability to complete ADL. Morris et al. (2012) found that upper extremity impairment is negatively associated with SRH. In their systematic review of the factors associated with SRH in Parkinson's Disease, van Uem et al., (2015) reported a negative association between mobility and locomotion factors and SRH. On the other hand, a study of 270 community-dwelling individuals living with SCI reported no association between physical impairments and SRH. However, the impact of the injury on the participation in ADL was negatively associated with SRH (Barker et al., 2009). Soh et al. (2011) and Visser et al. (2008) found similar results. To clarify, mobility is related to the ability to ambulate whereas extremity impairments are assessed through bodily structure or function such as strength (Franceschini et al., 2010). The distinction between lower extremity impairment and mobility may be due to the role that mobility plays in enabling individuals to complete desired activities and maintaining some independence.

Studies testing the association between age and SRH show mixed outcomes. Barker et al. (2009) found no relationship between age and SRH across the lifespan of individuals living with SCI in the community. On the other hand, in a prospective study of 340 individuals living with SCI, Rivers, et al., (2018) found a negative association between older age and SRH. Similarly, higher levels of SRH are associated with younger age (Alcañiz & Solé-Auró, 2018; Forslund et al., 2013). In contrast to SRH, older adults have been shown to display higher levels of SRMH

related to better coping strategies and greater optimism about their health (Hill et al., 2013; Layes et al., 2013).

Several reasons justify the differences in SRH and SRMH over the lifespan. Increasing age is associated with greater physical impairments, which is negatively associated with SRH in older populations (Forslund et al., 2013; Rivers et al., 2018). Alternatively, reported differences in SRH may reflect changing patterns, acceptance of the condition, and the dynamic interaction between PEO variables over a lifespan (Forslund et al., 2013; Nelson et al., 2003; Winter et al., 2010, Vrkljan, 2008). For instance, older patients may also be more accepting of disability and impairment as they are perceived as being appropriate to their age (Lawson et al., 2014).

### **2.10.2 AFFECTIVE FACTORS ASSOCIATED WITH SELF-REPORTED HEALTH**

The incidence of self-reported diagnosed mood or anxiety disorder among Canadian adults with a neurological condition is almost three times the rate of the Canadian population without neurological conditions (Bray et al., 2014). The presence of depressive or anxiety symptoms are negatively associated with SRH across a range of neurological conditions, including but not limited to ALS (Sandstedt et al., 2016), epilepsy (Johnson et al., 2004; Kwan et al., 2009), Huntington's disease (Ho et al., 2009), multiple sclerosis (Benito-Leon et al., 2002; Berrigan et al., 2016), spinal cord injury (Tate et al., 2015), Parkinson's Disease (Fan et al., 2016; Kadastik-Eerme et al., 2015; van Uem et al., 2016) and TBI (Williamson et al., 2013).

A negative relationship has been reported between depressive symptoms and SRH; the more frequent and severe the symptoms of depression, the lower the SRH (Gilliam, 2002). This relationship exists between diagnosis of major depression and SRH as well as between



depressive symptoms and SRH, with the level of depressive symptoms considered more relevant to SRH (Berrigan et al., 2016; Johnson et al., 2004; van Uem et al, 2016). The relationship to depressive symptoms is considered important because the threshold for diagnosis using the DSM criteria may mask the experience of depression associated with neurological conditions (Goldman Consensus Group, 2005; Koch et al., 2015; Patten et al., 2003). There is some suggestion that the presence of depressive symptoms in neurological conditions may be largely static and unrelated to disease course or disability (Koch et al., 2015). On the other hand, in their longitudinal analysis of 233 individuals living with SCI, Bonanno, et al. (2012) found several patterns of depression over time. The authors reported a pattern of stable low symptoms, a pattern of high symptoms followed by improvement, a pattern of delayed symptom elevations, and a chronic high depression group. This pattern or trajectory was not observed with anxiety.

The presence of anxiety symptoms is also negatively associated with SRH amongst people with a neurological condition (Kwan et al., 2009; Sandstedt et al., 2016). However, how anxiety and depression influence SRH and SRMH may vary between neurological conditions. Prisdie et al. (2018) explored the relative impact of anxiety and depression on SRH in 1,197 individuals with five neurological conditions, epilepsy, migraine, MS, stroke, and PD. The researchers reported that depression and anxiety were negatively associated with SRMH in the cohort with epilepsy and Parkinson's disease. In comparison, anxiety and depression were negatively associated with SRH in the stroke cohort. Finally, in the migraine and multiple sclerosis cohort anxiety and depression were negatively associated with SRH and SRMH. The authors suggested that the presence of physical impairments, in a condition like stroke, may be negatively associated with SRH, whereas conditions with greater stigma, such as epilepsy, may lead to lower levels of SRMH.

Self-efficacy is positively associated with SRH in neurological conditions (Robinson-Smith, Johnston & Allen, 2000; Stephens et al., 2016). Self-efficacy, introduced in the social-cognitive theory, is the belief that one can successfully influence the outcome of challenging situations through the performance of specific behaviours (Bandura, 2004). In adults living with a chronic neurological condition, higher levels of self-efficacy have been associated with lower levels of depression, higher levels of self-management, and lower perceived cognitive impairment (Hughes et al., 2015). In a study by Shneck et al. (1997) the authors found that individuals with SCI had higher levels of self-efficacy and lower levels of helplessness compared to individuals with the typically unpredictable pattern of MS. The unpredictable nature of a condition like MS may negatively impact an individual's belief that they can influence the outcome of their condition. Thus, unless people believe they can produce desired effects by their actions, they have little incentive to act or to persevere in the face of difficulties (Bandura, 2004).

### **2.10.3 COGNITIVE FACTORS ASSOCIATED WITH SELF-REPORTED HEALTH**

Cognitive impairment, including impairment in concentration and memory, behavioural dysregulation, and executive dysfunction, are consistent complications in most neurological conditions (Bray et al., 2014), including Parkinson's disease (Lawson et al., 2014), stroke (Nys et al., 2006) and TBI (Gorgoraptis et al., 2019). In a Canadian population with neurological conditions, cognitive impairment was reported by 18-93% of respondents, depending on the condition (Bray et al., 2014). Cognitive impairments are believed to negatively impact SRH by interfering with participation in daily activities (Foster & Hershey, 2010; Lawson et al., 2014; Shrag et al., 2000).

Despite the negative effects on functional outcomes, it is not clear whether cognitive impairment has a direct impact on SRH. Early cognitive impairment has been negatively associated with SRH in individuals living with stroke 6-10 months post injury (Nys et al., 2006). Furthermore, in a 10-year follow-up of individuals living with TBI, cognitive impairment was negatively associated with SRH (Rauen et al., 2020). The researchers also found that autonomy was positively associated with SRH, suggesting that less cognitive impairment led to greater autonomy which led to better SRH. Self-efficacy may also play a mediating role in this relationship. Hughes et al. (2015) found higher self-efficacy associated with lower levels of perceived cognitive impairment. It is possible that higher self-efficacy could be associated with a greater ability to mitigate the impact of cognitive impairment and therefore SRH.

Cognitive impairment in neurological conditions does not typically occur in isolation, which complicates its influence on SRH. For example, depression, fatigue, and sleep disturbance commonly coexist with cognitive impairment, and all are known to affect cognitive function as well as SRH (Gorgoraptis et al., 2019). Glanz et al. (2010) reported that while there was no difference in SRH between individuals living with cognitive impairment and those who were not, cognitive impairment was negatively associated with depression and fatigue. Lawson et al., (2014) found a negative relationship between cognitive impairment and SRH in individuals with Parkinson's disease. In this case, there appeared to be a threshold with very mild cognitive impairment having no relationship to SRH.

There is also the possibility that cognitive impairment is associated with impaired self-awareness (Sherer et al., 1998), which can lead to higher assessments of SRH (Sasse et al., 2013). Shrag et al. (2000) found that limited self-awareness results in higher SRH, particularly related to cognitive impairment, in those living with Parkinson's disease. The authors also

reported that an overestimation of competencies was positively associated with SRH. It is therefore possible that cognitive impairment may be unexpectedly positively associated with SRH (Gorgoraptis et al., 2019).

## **2.11 ENVIRONMENTAL FACTORS ASSOCIATED WITH SELF-REPORTED HEALTH**

As previously stated, within the PEO Model, the environment is defined as the context in which the individual engages in occupations. It includes cultural, institutional, physical, and social-economic aspects with each, theoretically, having an enabling or constraining impact on one's ability to participate in desired occupations and SRH (Law et al., 1996; Wilcock, 2007). This is consistent with research that shows that SRH can be influenced by social determinants of health, such as income, assistance, and stigma (Bray et al., 2014).

Based on data from a decade ago, a third of adults living with a neurological condition in Canada experienced a financial crisis at some juncture (Bray et al., 2014). Lower income has a negative association with SRH in adults living with a chronic neurological condition (Janzen et al., 2013; Nelson et al., 2003; Schrag et al., 2000). Similarly, higher incomes are positively associated with SRH. Of 300 respondents in a group of Canadians living with MS, higher income was one of two consistently positive predictors of better SRH (Hopman et al., 2007). Given that roughly sixty percent of Canadians living with a neurological condition reported out-of-pocket costs for medical costs, higher income may lead to greater SRH via access to necessary supports for health maintenance and the participation in desired activities (Bray et al., 2014;

Hopman et al., 2007). Higher income is also important for access to housing and food security, which are positively associated with SRH (Frier et al., 2017).

The need for support services and interventions is negatively associated with SRH (Hopman et al., 2007). SRH is also positively influenced by higher levels of social support and the ability to be independent (Yamout et al., 2013; Winter et al., 2011; Winter et al., 2010). In a qualitative study of 27 individuals living with neurological conditions, respondents reported that assistance improved their lives for the better (Ahlström, 2006). However, the results indicated that individuals who were dependent on the help of assistance developed some degree of helplessness. It is therefore conceivable that the need for assistance is indirectly related to SRH through other variables such as disease severity, self-efficacy, and independence. For example, Hahn et al. (2018) reported that those who receive assistance are in later stages of the disease are older, less educated, and have poorer functional and cognitive skills.

Stigma, defined as the negative beliefs, attitudes, prejudice and discrimination of a group, and associated internalized perceptions of those attitudes, has a negative association with SRH for adults living with a chronic neurological condition (Gershon et al., 2011; Rao et al., 2009). Based on Canadian data, 5% to 36% of Canadians with a neurological condition experience perceived stigma (Bray et al., 2014). These perceptions are experienced as being left out of activities, feeling that others are uncomfortable around them or avoiding them, or embarrassment about their condition (Bray et al., 2014). As a result, stigma is considered to have a negative influence on SRH through lowered self-efficacy, anxiety, depression, the ability or desire to access necessary supports and desired roles and activities (Victorson et al., 2014). There is some literature to suggest that personal reactions to stigma may play a role in the impact of stigma on SRH. Corrigan and Watson (2002) stated that stigma may result in low levels of self-esteem and

self-efficacy for some while others may be energized. Therefore, it is possible that not everyone experiences stigma in the same way.

## **2.12 OCCUPATIONAL FACTORS ASSOCIATED WITH SELF-REPORTED HEALTH**

According to the PEO Model, engagement in occupation includes consideration of roles, activities, and tasks that an individual engages in to “meet their intrinsic needs for self-maintenance, expression, and fulfillment” (Vrkljan, 2010, p. 398). It includes both the ability to participate in daily activities that are essential for survival as well as social roles required for well-being (Desrosiers et al. (2006).

In general, having the ability to participate in and satisfaction with occupations are positively associated with SRH. On the other hand, an inability to participate in and less satisfaction with occupations are associated with social isolation and lower SRH (Forslund et al., 2013; Hartman-Maeir et al, 2007; Mayo et al., 2002; Warner et al., 2018; Winter et al., 2011). In a randomized trial of 210 individuals living with Parkinson’s disease, activity limitations were found to be negatively associated with SRH (Soh et al., 2011). Similarly, in a sample of 270 individuals living with spinal cord injury, Krhan et al. (2009) noted “what appears important is the ability to carry out one’s roles, regardless of how that is accomplished.” (p. 583). Also consistent with these findings, Hartman-Maeir et al. (2007) found that satisfaction with activities of daily living and instrumental activities of daily living were positively associated with functional outcomes in 56 stroke patients one-year post injury.

A recent study of individuals living with a chronic neurological condition found that SRH was related to different aspects of occupation (Warner et al., 2018). Using secondary analysis of

88 subjects the researchers compared the clinical and environmental factors associated with accomplishment and satisfaction in social roles. The authors used the LIFE-H to measure dependent variables, accomplishment in social roles, and satisfaction with social roles. In the context of this study, SRH and SRMH were two independent, clinical variables. For the domains of accomplishment in social roles, SRH was positively associated with the accomplishment domains of responsibilities, interpersonal relationships, recreation, and the total accomplishment score. In comparison, SRH was positively associated with the total satisfaction scale of social roles and recreation. It appears that how an individual experiences occupation influences their SRH.

In the same study by Warner et al., (2018), of the six social role domains, employment was the only social role to which SRMH was significantly correlated. Social roles not associated with SRMH included responsibility, interpersonal relationships, community life, education, and recreation. As a specific occupation, employment, or more appropriately, a lack thereof, is associated with lower SRH amongst working-age adults living with a chronic neurological condition (Cioncolini et al., 2014; Janzen et al., 2013; Yamout et al., 2013). Employment has direct financial implications with greater income resulting in greater access to resources as well as increased support (Shrag et al., 2000; Winter et al., 2010). A lack of employment is negatively associated with SRH and increased levels of disability (Frier et al., 2017).

Finally, although discussed previously in relation to person-level factors, SRH and occupation variables may also be influenced by underlying impairments or disease severity. In their study of 102 patients with Myasthenia gravis, Raggi et al., (2010) found that there was a direct relationship between disease severity, occupation, and SRH. Those with more severe disease severity had greater restrictions in participation and lower SRH and SRMH.

Consequently, ability and satisfaction may be a marker for disease severity; lower levels of the disease severity may allow for greater ability and satisfaction with roles and activities.

### **2.13 SUMMARY**

This section has summarized the current literature related to PEO factors on SRH and SRMH across neurological conditions. Individuals living with neurological conditions experience diminished SRH and SRMH in the context of P, E, and O level factors. While differences exist between conditions, persons with different neurological conditions share many of the same effects. The needs of this group may be similar, to varying degrees, across conditions. However, no study to date has examined the associations between these factors and SRH and SRMH across neurological conditions using a comprehensive model. The assessment and understanding of the factors associated with SRH and SRMH and understanding their major determinants is important to understanding the broad health-related impacts of chronic neurological conditions and guiding and evaluating rehabilitation interventions.

### **2.14 RESEARCH QUESTION**

This research explored the person, occupation, and environment-related factors associated with SRH in adults living in Canada with a chronic neurological condition. More specifically, using the PEO Model as a theoretical framework, the following question was answered for Canadian adults living with a chronic neurological condition:



- 1) What PEO factors are associated with SRH and SRMH for adults living in Canada with a chronic neurological condition?

## CHAPTER 3 FACTORS ASSOCIATED WITH GENERAL HEALTH AND MENTAL HEALTH IN PEOPLE LIVING WITH CHRONIC NEUROLOGICAL CONDITIONS

*This chapter is intended for publication. This chapter was primarily written by Jason Lomond with contributions from Dr. Tanya Packer and Dr. Grace Warner.*

### 3.1 ABSTRACT

**Purpose:** The purpose of this study was to explore the factors associated with self-reported general health and mental health for adults living in Canada with chronic neurological conditions.

**Materials and methods:** A secondary analysis of data from a sample of participants drawn from the Living with the Everyday Impact of a Neurological Condition (LINC) study was conducted. Specific inclusion criteria for this study were adults, aged 17 and over, living in Canada with a range of chronic neurological conditions. Independent variables were organized according to the Person Environment Occupation (PEO) Model.

Linear regression analysis identified factors associated with self-reported general health and self-reported mental health.

**Results:** Self-reported general health and self-reported mental health were most influenced by ‘person’ factors. Self-reported general health was most influenced by fatigue and self-efficacy, while self-reported mental health was most influenced by depression.

**Conclusion:** Person-level factors, depression, fatigue and self-efficacy, had the greatest influence on self-reported general and self-reported mental health for people living with chronic

neurological conditions. Models of care that explicitly assess and address depression, fatigue and self-efficacy are more likely to improve the health and mental health of people living with neurological conditions

**Keywords: health, mental health, neurological conditions, self-efficacy, depression, fatigue**

### **3.2 IMPLICATIONS FOR REHABILITATION**

- Interventions to address fatigue may improve self-reported general health for people living with chronic neurological populations.
- Interventions to address depression may improve self-reported mental health for people living with chronic neurological conditions.
- Interventions to increase self-efficacy may improve both general health and mental health for people living with chronic neurological conditions.

### 3.3 INTRODUCTION

Neurological conditions are a worldwide cause of death and disability, negatively impacting self-reported general health (SRH) and mental health (SRMH) for individuals with those conditions (CIHI, 2007; Bray et al., 2014; WHO, 2006). In 2006, neurological conditions were documented to affect roughly a billion people globally, which accounted for 6.3% of the total global burden of disease (WHO, 2006). A decade later, neurological conditions were responsible for 276 million disability life adjusted years (DALYs) or 11.6% globally for all diseases and were the underlying cause in 16.5% of total global deaths (Feigin et al., 2017). Based on these numbers, globally, neurological conditions are the second leading cause of death and the leading cause of disability (Carroll, 2019).

The burden of neurological conditions in Canada is consistent with the global impact. In 2007, neurological conditions were responsible for 10.6% of total disability adjusted life years (DALYs) for illness in Canada (Tator, et al., 2007). By 2031 models predict that more Canadians living with neurological conditions will experience severe disability and, depending on the condition, will lose 14 to 41 equivalent years of life living in full health (PHAC, 2014). There are also significant economic costs. In 2008, neurological conditions were estimated to cost roughly \$192.8 billion Canadian dollars a year, which was a 13.8% increase from 2005 to 2008 (PHAC, 2014).

As evident from the data, the burden of neurological conditions is significant and continues to increase. While age-standardized incidence, mortality, and prevalence rates of many neurological disorders declined for the past three decades, the absolute number of people dying or remaining disabled from neurological disorders over the past quarter century has been increasing (Feigin et al., 2017). Moreover, people are living longer with these conditions (Gaskin

et al., 2017). This is notable given that Canadians living with a neurological condition report fair to poor levels of SRH roughly three times more frequently than the general population (Gaskin et al., 2017; PHAC, 2014; WHO, 2006).

As a subjective evaluation, SRH indicates a person's overall perception of their health and is more sensitive in monitoring total health than more objective measures, which may not capture the full impact of a disease (Bonner et al., 2017; Cella et al., 2012; Idler & Benyamini, 1997; Miilunpalo et al., 1997). SRMH is also affected. Compared to the general population, a greater proportion of Canadians with a neurological condition report high levels of stress or a diagnosis of a mood or anxiety disorder (Bray & Huggett, 2016).

As populations are growing and aging, and neurological conditions increase with age, governments will encounter mounting pressure for treatment, rehabilitation, and support services for people with neurological conditions (Feigin, 2016). In addition to the consequences already mentioned, individuals living with these conditions can be impacted by impairments related to mobility, upper extremity function, and cognition as well as greater levels of stigma (PHAC, 2014). Because neurological conditions are, for the most part, managed, not cured, it is crucial to identify those factors that directly or indirectly contribute to better SRH. SRH has been identified as a predictor of mortality, physical functioning, health services utilization and provides insight into how individuals perceive the impact of disease on their life (Bonner, et al., 2017, Soh et al., 2012). Addressing variables related to SRH will enable rehabilitation professionals and healthcare systems to direct resources towards factors that have the greatest potential to enhance the lives of those living with neurological conditions and reduce the associated burden.

To achieve this objective, new treatments and rehabilitation approaches are needed to address the diverse impacts of neurological conditions (Bray et al., 2014). There is also

increasing recognition that health professionals should look beyond the disease, impairments, and associated deficits (Turner et al., 2009). Service providers and policymakers have advocated the need for models of care that shift the emphasis from diagnosis to functional requirements to meet patient needs and improve SRH (Bray & Huggett, 2016; Jaglal et al., 2014). This approach to understanding rehabilitation with neurological conditions embraces the concept that living with a chronic condition goes beyond knowledge of disease mechanisms (Josman et al., 2020). Compared to people of the same relative age, more Canadians with a neurological condition with “poor” or “fair” SRH report limitations of usual activities or are permanently unable to work (Bray & Huggett, 2016).

The concept of participation in everyday occupations has emerged as a key concern in rehabilitation theory, clinical practice (McLean et al., 2014) and is considered an important rehabilitation outcome (WHO, 2002). Better SRH and SRMH have been reported by individuals living with a chronic neurological condition with fewer restrictions with participation in daily activities (Andelic et al., 2010). Participation in everyday occupations represents an important rehabilitation outcome because it embodies the extent to which a person resumes an active role in valued personal and social pursuits (Stiers et al., 2012). Theoretically, occupational therapists believe that a relationship exists between occupational performance and SRH (Law et al., 1998; Wilcock, 1993). Occupational performance is defined as the subjective evaluation of an individual’s level of satisfaction and ability to perform daily occupations (Law et al., 1996). By engaging in occupation, an individual has the potential to satisfy needs related to meaning, purpose and social connectedness thereby improving SRH (Hammell, 2004).

The Person Environment Occupation (PEO) Model is a conceptual framework to understand the complex interrelationship among factors that contribute to occupational

performance (Law et al., 1996). This model provides a framework to understand how transactions between person, environment, and occupation factors combine to shape occupational performance. According to Law et al. (1996), the person is an individual with physical, cognitive, and affective qualities consequently having their own unique abilities, skills, identities, experiences, and motivations. The environment includes the social-economic, cultural, physical, and institutional contexts of each individual. Occupation refers to clusters of activities with inherent meaning that an individual participates or engages in to meet his or her needs or for a specific purpose.

Although participation in daily occupations has been positively associated with SRH within cohorts of individuals living with chronic neurological conditions (Forslund et al., 2013; Hartman-Maeir et al, 2007; Mayo et al., 2002; Warner et al., 2018; Winter et al., 2011), it is not clear if this finding is consistent across all neurological conditions. Most research on neurological conditions to date is diagnosis-specific (Auduly et al., 2014). It is also unclear how other contextual factors influence SRH and SRMH across neurological conditions. The assortment of factors that affect those living with a chronic neurological condition, such as physical and cognitive impairment, depression, and environmental variables individualize the experience (Kalpinski et al., 2013; McLean et al., 2014; O'Reilly et al., 2018). Understanding the association of occupational performance and confounding variables with SRH and SRMH across neurological conditions would enable healthcare professionals to design effective rehabilitation programs to meet patient needs and improve SRH and SRMH.

The aim of this study was, therefore, using the PEO Model as a guide, to determine which PEO factors are associated with SRH and SRMH for adults living in Canada with a chronic neurological condition. The findings from this study can provide direction to

rehabilitation professionals working to improve SRH and SRMH in adults living with a chronic neurological condition.

### **3.4 METHODS**

#### **3.4.1 SAMPLE**

The data for this secondary analysis was gathered in the first phase of the Living with the Everyday Impact of a Neurological Condition (LINC) study. Complete LINC study methods can be found in Versnel et al. (2013). Briefly, the first phase of the LINC study was a national survey, supplemented by two other phases that used a nested mixed-method design. It was undertaken to understand the lives of people living with a wide range of neurological conditions living in Canada. To be included in the LINC study, the respondents had to be residing in Canada, over the age of 16 and living with a neurological condition, or be a parent of a child (ages of 5-16) living with a neurological condition. Participants were primarily recruited via the Neurological Health Charities of Canada (NHCC) through its database and letters of invitation and telephone calls. Social media, posters, and media such as radio and television were also used to recruit individuals living with neurological conditions in Canada. Data in the first phase of the LINC study were collected from respondents through a self-report survey that took 60-90 minutes to complete. The primary method was an online version although a paper and pencil format or telephone interview were made available depending on the choice of respondents. Telephone interviews were conducted by trained research assistants to reduce bias.

For the current study, data for adults, aged 17 and over and living in Canada with chronic neurological conditions were extracted from the LINC dataset that captured information from the



national survey. Although the World Health Organization (WHO) defines an adult as 19 years or older unless otherwise stated by law, the lower boundary for adults in this study was defined as 17 years as that is considered the typical transition point to the next stage of productive life following high school (WHO, 2013). Data for respondents who met the age criteria and completed the demographic section of the survey were included. Respondents who identified as having only migraine were excluded because of variability in the severity of migraines and because participants with migraine and no other chronic conditions commonly have higher levels of self-reported health compared to people with other neurological conditions (Bray et al., 2014). Including them would have skewed the distribution of SRH and made the sample less representative of the population of individuals living with a chronic neurological condition. Participants age 16 and parents included in the LINC study were excluded from this analysis. For all components of this study, ethical approval was received from the Health Canada and Public Health Agency of Canada Research Ethics Board, as well as the appropriate ethics review boards at Dalhousie University, Queens University, the University of Manitoba, and the University of Prince Edward Island. Data collection in Newfoundland and Labrador was acknowledged by the provincial Health Research Ethics Authority. Informed consent was obtained from all participants for each stage of the study.

### **3.4.2 VARIABLES AND OUTCOME MEASURES**

Variables for this study were selected to represent elements in the PEO Model (Law et al., 1996). *Table 1* details the dependent variables SRH and SRMH and the independent PEO variables according to the PEO Model.

#### **Dependent Variables**

SRH and SRMH were assessed using the questions from the 2010-2011 Canadian Community Health Survey (CCHS) (Statistics Canada, 2010). SRH and SRMH variables in the CCHS were chosen because using a single-item outcome measure is a simple and easy-to-administer method to assess SRH and SRMH (Ahmad et al., 2014). The response scales for both measures were categorized as (0) poor (1) fair (2) good (3) very good and (4) excellent, with higher scores representing better levels of SRH and SRMH (Statistics Canada, 2010). The single-item measures of SRH and SRMH in the CCHS have been found to be valid and reliable measures for Canadian population-based studies involving persons living with chronic neurological conditions (Orpana et al., 2017; Rampage-Morin, Shields & Martel, 2010; Shields & Shooshtari, 2001; Yang, et al., 2017) including people with cognitive impairment (Baumstarck et al., 2013).

### **Independent Variables**

Independent variables were selected based on their associations with SRH and SRMH in individuals living with neurological conditions that have been reported in the research literature. Variables were subsequently categorized as P, E, and O variables based on the PEO Model. The selected variables are briefly described below, organized alphabetically according to the relevant measurement tool or survey.

**CCHS (2010-2011):** Three CCHS items assessed person variables; age (1 = < 27, 2 = 27-55, 3 = 56-65, 4 = > 65); education (0 = some post-secondary, secondary or less, 1 = post-secondary graduation) and gender (1 = Male, 2 = Female, 3 = Do not wish to answer) (Statistics Canada, 2010).

Three items from the 2010-2011 CCHS were used to assess environment variables: assistance (0 = no assistance, 1 = some form of assistance); income (1 = < \$20,000, 2 = 20,000-59,999, 3 = 60,000-89,999, 4 = > 90,000); and marital status (1 = single/never married, 2 = married/common law, 3 = widowed/divorced/separated).

Finally, one item from the 2010-2011 CCHS assessed occupation: employment (1 = working, 2 = not working due to health, 3 = not working due to other reasons).

**Neuro-QOL:** The Quality of Life Outcomes in Neurological Disorders (Neuro-QOL) is a set of self-report measures developed to assess symptoms and concerns of adults and children living with neurological disorders (Gershon et al., 2012). It was specifically developed to be appropriate for a range of neurological conditions and is not disease-specific. The evidence thus far on the development of the Neuro-QOL item banks and short forms has demonstrated high reliability, good construct, and content validity, as well as responsiveness to change for a variety of neurological conditions (Bode et al., 2010; Gershon et al., 2012; Miller et al., 2016; Nowinski et al., 2010; Nowinski et al., 2016; Salsman et al., 2013; Tulskey et al., 2016; Tulskey et al., 2015).

For this study, the following Neuro-QOL sub-domain scales, published in 2010, were used. P variables were assessed with the following scales: (a) Anxiety, (b) Applied Cognition - General Concerns, (c) Applied Cognition - Executive Function, (d) Depression, (e) Fatigue, (f) Lower Extremity Function/Mobility, (g) Sleep Disturbance and (h) Upper Extremity/Fine Motor Function. To assess E variables, the Stigma scale was used. Finally, to assess O variables the following scales were used: (a) Ability to Participate in Social Roles and Activities and (b) Satisfaction with Social Roles and Activities. All Neuro-QOL responses used an ordinal, five-item Likert-type response scale ranging from least to most, based on the frequency of behaviour,

amount of difficulty, or degree of agreement. The responses for each item were summed to create a total score for each scale, which were converted to a T-score with a mean of 50 and a standard deviation of 10 with a higher Neuro-QOL T-score representing more of the concept being measured (Gershon et al., 2012).

**SEMCD:** The 6-item Self-Efficacy for Managing Chronic Disease Scale (SEMCD) is a 6-item scale with each item rated using a visual analog scale, ranging from 1 (not at all confident) to 10 (totally confident), with higher scores representing higher levels of self-efficacy (Ritter & Lorig, 2014). The SEMCD has demonstrated high internal consistency, minimal floor and ceiling effects, and minimal sensitivity to change (Freund et al. 2013; Riehm et al.; Ritter & Lorig, 2014). Conversely, it has demonstrated weakness in structural validity related to the underlying concept of self-management and convergent validity to other self-management tools (Kephart et al., 2019). However, these weaknesses do not affect its ability to assess person-level self-efficacy.

**SLNCC (2011-2012):** The Survey on Living with Neurological Conditions in Canada (SLNCC), included in the 2011-2012 CCHS, was part of a national, cross-sectional health survey designed to explore issues among Canadians aged 15 and older with chronic neurological conditions. Responses on all items were categorized as (1) not at all to a little bit (2) moderately (3) quite a bit or (4) extremely (SLNCC, 2007).

The SLNCC was used to assess three person variables: (1) number of neurological conditions (1 = 1 condition, 2 = 2-7 conditions), (2) number of non-neurological conditions (0 = none, 1 = 1-3 non-neurological conditions, including diabetes, depression and heart disease) and (3) number of years since onset (0-71 years).

A question from the SLNCC, “Overall, how much do you feel that your neurological condition(s) affects your life?”, was used to assess the occupation variable by examining the limitations on daily activities.

**Table 1: PEO Model and Study Variables**

<b>Variables</b>	<b>Definition</b>	<b>Measurement Tools</b>
Self-Reported General Health	Global evaluation of health performed by subjective self judgement.	<ul style="list-style-type: none"> <li>• Canadian Community Health Survey</li> </ul>
Self-Reported Mental Health	Global evaluation of mental health performed by subjective self judgement.	<ul style="list-style-type: none"> <li>• Canadian Community Health Survey</li> </ul>
Person Physical	Physical includes sensory, motor and sensorimotor functions.	<ul style="list-style-type: none"> <li>• Neuro-QoL Upper Extremity</li> <li>• Neuro-QoL Lower Extremity Function</li> <li>• Neuro-QoL Fatigue</li> <li>• Age</li> <li>• Gender</li> <li>• Neuro-QoL Sleep Disturbance</li> <li>• Non-Neurological Comorbidity</li> <li>• Number of Years Since Onset</li> <li>• Total Neurological Conditions</li> </ul>
Person Cognitive	All mental functions, both cognitive and intellectual, and includes, among other things, perception, concentration, memory, comprehension, judgement and reasoning.	<ul style="list-style-type: none"> <li>• Neuro-QoL Applied Cognition - General Concerns</li> <li>• Neuro-QoL Applied Cognition - Executive Function</li> <li>• Education Level</li> </ul>
Person Affective	Social and emotional functions, including motivation, drives and confidence.	<ul style="list-style-type: none"> <li>• Neuro-QoL Depression</li> <li>• Neuro-QoL Anxiety</li> <li>• Self-Efficacy for Managing Chronic Disease Scale</li> </ul>
Environment	Social-economic, cultural, physical and institutional contexts.	<ul style="list-style-type: none"> <li>• Assistance</li> <li>• Income</li> <li>• Marital Status</li> <li>• Neuro-QoL Stigma</li> </ul>

<b>Variables</b>	<b>Definition</b>	<b>Measurement Tools</b>
Occupation	Clusters of functional activities with inherent meaning that an individual engages in to meet his or her needs or for a specific purpose.	<ul style="list-style-type: none"> <li>• Neuro-QoL Ability to Participate in Social Roles and Activities</li> <li>• Neuro-QoL Satisfaction with Social Roles and Activities</li> <li>• Employment</li> <li>• Restriction of Daily Activities (Survey on Living with Neurological Conditions in Canada)</li> </ul>

### 3.4.3 DATA ANALYSIS

Descriptive statistics were first calculated for all variables. This was followed by bivariate measures of association between independent and dependent variables, followed by ordinary least squares (OLS) regression analysis to test which variables were significantly associated with SRH and SRMH after controlling for other PEO variables.

Data for variables of interest were extracted and transferred from the main LINC dataset by one of the principal investigators. Items with too few responses per response category to provide acceptable comparison were collapsed. Descriptive statistics used to describe the sample included the mean and standard deviations for continuous variables, and frequencies and percentages for dichotomous and categorical variables. Bivariate analysis examined the associations between each of the independent and dependent variables using Spearman correlations for continuous and ordinal variables and, Mann-Whitney U-Test or Kruskal Wallis for categorical independent variables. P, E, and O variables that were significantly associated ( $p < 0.1$ ) with and had limited collinearity to the relevant dependent variable, SRH or SRMH, were

retained for the final model. Age, gender, and income were included in the regression as known demographic variables regardless of significance.

Multicollinearity was assessed between and amongst dependent and independent variables using a correlation of  $r > 0.8-0.9$  as the threshold for indicating multicollinearity (Field, 2018). Multicollinearity was also assessed in the regression analysis using collinearity statistics of tolerance and variance inflation factor (VIF). Tolerance  $< 0.2$  or a large VIF  $> 10$  indicates a potential problem with multicollinearity (Field, 2018).

Ordinal regression and backward OLS linear regression techniques were attempted for the final analysis with backward OLS linear regression chosen for the final model. The OLS linear regression was chosen because ordinal regression yielded significant warnings of zero frequencies, suggesting there were combinations of variables for which there were no observations. Combinations of variables with no observations are inevitable with so many categorical and continuous variables (Field, 2018). The large number of zero frequencies resulted in unreliable Pearson and Likelihood Ratio model goodness of fit tests. The proportional odds assumption for SRH was also rejected for the ordinal regression model as it violated the test of parallel lines (.005). Ultimately, although the dependent variable was ordinal, the use of linear regression techniques for Likert type items has been supported in the literature. Manderbacka et al. (1998) found that SRH forms a continuum when risk factors and ill health are considered. Furthermore, several researchers have treated SRH as a continuous variable with equidistant categories (Garbarski et al., 2015; Jürges et al., 2008). Linear regression techniques have also been used with Likert type items with minimal effect on the tests of significance as the results turn out to be nearly identical, demonstrating robustness even when statistical assumptions are violated (Hellevik, 2009; Norris et al., 2006; Sullivan & Artino Jr., 2013).

Backward OLS linear regression process was used to simultaneously enter all the independent variables into the regression model for each dependent variable, then by running successive models the least significant variable was excluded from the subsequent model until all remaining variables demonstrated statistical significance ( $p \leq 0.05$ ). (Field, 2018). This process was repeated for each dependent variable, creating separate SRH and SRMH models.

### 3.5 RESULTS

#### 3.5.1 SAMPLE

A total of 750 respondents met the inclusion criteria. These participants were predominantly between the ages of 27-65 (76.4%), female (64.3%), married (62.1%), and well educated (72.3% post-secondary graduates) (*Table 2*). Only 70% of respondents reported their household income with 17.1% of those reporting an annual household income less than \$20,000. Just over half of the respondents (51.6%) reported needing financial or other forms of assistance.

**Table 2: Summary Statistics for Categorical Dependent and PEO Variables**

PEO Variables	Frequency	Percent
<b>Dependent Variables</b>		
<b>Self-Rated General Health (n = 744)</b>		
Poor	58	7.8
Fair	186	25.0
Good	293	39.4
Very Good	161	21.6
Excellent	46	6.2
<b>Self-Rated Mental Health (n = 735)</b>		
Poor	55	7.5
Fair	124	16.9
Good	216	29.4
Very Good	216	29.4
Excellent	124	16.9



PEO Variables	Frequency	Percent
<b>Person Variables</b>		
<b>Gender (n = 746)</b>		
Male	266	35.7
Female	480	64.3
<b>Education Level (n = 718)</b>		
Some post-secondary, secondary or less	199	27.7
Post-secondary graduation	519	72.3
<b>Age (n = 747)</b>		
<=26	45	6.0
27-55	391	52.3
56-65	180	24.1
>65	131	17.5
<b>Non-neuro comorbidity (n = 748)</b>		
None	383	51.2
1-3	365	48.8
<b>Total Neurological Diagnosis (n = 750)</b>		
1	468	62.4
2-7	282	37.6
<b>Environment Variables</b>		
<b>Household Income (n = 525)</b>		
< \$20,000	90	17.1
\$20,000 TO \$59,999	202	38.5
\$60,000 TO \$ 89,999	107	20.4
\$90,000 or MORE	126	24.0
<b>Marital Status (n = 746)</b>		
Single, never married	164	22.0
Married or Common-law	463	62.1
Widowed, Separated, Divorced	119	16.0
<b>Assistance (n = 739)</b>		
No Support	358	48.4
Assistance	381	51.6

PEO Variables	Frequency	Percent
<b>Occupation Variables</b>		
<b>Employment Status (n = 735)</b>		
Working	241	32.8
Not working due to health	276	36.8
No working due to other reasons	218	29.1
<b>Affect Daily Activities (n = 746)</b>		
Not at all to a little bit	143	19.2
Moderately	175	23.5
Quite a Bit	205	33.5
Extremely	178	23.9

The most frequently reported neurological conditions were multiple sclerosis (23.3%), Parkinson’s disease (20.4%), brain injury (14.8%), and epilepsy (13.6%). Other neurological conditions, including muscular dystrophy, dystonia, spinal cord injury, stroke, spina bifida, hydrocephalus, amyotrophic lateral sclerosis, brain or spinal cord tumor, cerebral palsy, Alzheimers disease, Tourettes syndrome and Huntington’s disease, were reported in percentages of less than 10% (*Table 3*). While 27.6% of participants reported having two neurological conditions, most (62.4%) reported having a single neurological condition. The mean length of time from diagnosis was 17.3 years.

**Table 3: Summary of Conditions**

Condition	Frequency	Percent
Multiple Sclerosis	173	23.3
Parkinson’s Disease	152	20.4
Brain injury	107	14.8

<b>Condition</b>	<b>Frequency</b>	<b>Percent</b>
Epilepsy	101	13.6
Muscular Dystrophy	68	9.2
Other Neurological Condition	64	8.5
Dystonia	47	6.6
Spinal Cord Injury	46	6.3
Stroke	41	5.6
Spina Bifida	36	4.8
Other Neuromuscular	35	4.7
Hydrocephalus	32	4.3
Amyotrophic Lateral Sclerosis	28	3.8
Brain or Spinal Cord Tumour	21	2.8
Cerebral Palsy	14	1.9
Other Neuropsychiatric	12	1.6
Alzheimers Disease	10	1.4
Tourettes Syndrome	7	0.9
Huntington's Disease	7	0.9

The mean *T*-Score for all the Neuro-QOL measures was close to 50 or less than 1 standard deviation from the mean (*Table 4*). The variables Upper Extremity/Fine Motor Function, Lower Extremity Function/Mobility, Applied Cognition - General Concerns, Applied Cognition - Executive Function and Ability to Participate in Social Roles and Activities had a distribution skewed towards higher, more positive scores. Depression, anxiety, and stigma measures had a distribution skewed towards lower, more positive scores.

**Table 4: Summary Statistics for Continuous Dependent and PEO Variables**

Variable	Observations (number)	Mean	Standard Deviation	Range Min	Range Max
<b>Person Variables</b>					
Neuro-QOL (T-scores)					
Anxiety	748	50.2	8.7	36	77
Applied Cognition – Executive Functioning	746	43.3	10.5	13	58
Applied Cognition – General Concerns	745	42	9.7	20	59
Depression	746	48.8	8.8	37	75
Fatigue	746	51	8.7	30	74
Lower Extremity Function	745	43.4	11.5	17	59
Upper Extremity Function	744	42.5	10.9	13	54
Sleep	748	53.1	9.2	32	84
Self-Efficacy for Managing Chronic Disease Scale	742	6.2	2.2	1	10
Time From Diagnosis (years)	738	17.3	15.0	0	71
<b>Environment Variables</b>					
Neuro-QOL (T-scores)					
Stigma	745	52.5	7.8	39	82
<b>Occupation Variables</b>					
Neuro-QOL (T-scores)					
Ability to Participate in Social Roles	741	45.8	7.8	24	60
Satisfaction with Social Roles and Activities	741	44.2	5.8	28	61

### Self-Reported General Health and Self-Reported Mental Health

Roughly two-thirds of participants rated their SRH (67.2%) and SRMH (75.7%) as good, or higher with responses categorized from (0) poor (1) fair (2) good (3) very good (4) excellent.

### **3.5.2 BIVARIATE ANALYSIS**

The bivariate tests of association between independent variables and the two dependent variables SRH and SRMH were similar (*Table 5*). None of the variables demonstrated multicollinearity. Nine of the fifteen person-level variables, including anxiety, depression, fatigue, both applied cognition measures, number of non-neurological conditions, number of neurological conditions, self-efficacy, and sleep met the threshold ( $p < 0.1$ ) for inclusion in the final models for both SRH and SRMH . Three of the four environment variables, including income, marital status and stigma met the threshold for inclusion in the final model. Finally, all occupation variables, including ability to participate in social roles and activities, satisfaction with social roles and activities, restrictions of activities of daily living and employment met the threshold for inclusion for the final model.

In addition, three person-level variables (i.e. upper extremity function, lower extremity function, and education) and one environment variable (assistance) met the threshold for inclusion in the SRH model. No further person variables to those previously mentioned met the threshold to be included in the final model for SRMH. Gender and time since diagnosis did not meet the threshold for either of the final models; however, gender and age were retained to control for demographic variables in the regression analysis.

**Table 5: Results from the bivariate analysis**

Variable	Dependent Variables	
	CCHS: Self-reported General Health <i>p</i>	CCHS: Self-reported Mental Health <i>p</i>
<b><u>PERSON</u></b>		
Neuro-QOL Upper Extremity	.000*	.875
Neuro-QOL Lower Extremity	.000*	.791
Neuro-QOL Fatigue	.000*	.000*
Age	.161	.000*
Gender	0.799	.655
# Non-Neuro Conditions	.000*	.000*
# Neuro Conditions	.002*	.000*
Time since diagnosis	0.710	0.914
Neuro-QOL General Cognition	.000*	.000*
Neuro-QOL Executive Functions	.000*	.000*
Education Level	.014*	.948
Neuro-QOL Depression	.000*	.000*
Neuro-QOL Anxiety	.000*	.000*
Self-Efficacy for Managing Chronic Disease Scale	.000*	.000*
Neuro-QOL Sleep	.000*	.000*

Variable	Dependent Variables	
	CCHS: Self-reported General Health <i>p</i>	CCHS: Self-reported Mental Health <i>p</i>
<b><u>ENVIRONMENT</u></b>		
Assistance	.000*	.139
Income	.002*	.000*
Marital Status	.099*	.020*
Neuro-QOL Stigma	.000*	.000*
<b><u>OCCUPATION</u></b>		
Neuro-QOL Ability to Participate	.000*	.000*
Neuro-QOL Satisfaction with Roles	.000*	.000*
Affect Daily Life	.000*	.000*
Employment	.000*	.000*

\* indicates variables included in final model

### 3.5.3 OLS LINEAR REGRESSION RESULTS

The results of the OLS linear regression analyses for both dependent variables, SRH and SRMH, are presented in *Table 6*. Model fit statistics were 37.3% and 55.1% for SRH and SRMH respectively.

**Table 6: Linear Regression Results**

Variable	Dependent Variables					
	Self-Reported General Health			Self-Reported Mental Health		
	$\beta$	$\rho$	VIF	$\beta$	$\rho$	VIF

Variable	Dependent Variables					
	Self-Reported General Health			Self-Reported Mental Health		
<b><u>PERSON VARIABLES</u></b>						
Age	-0.101	0.010	1.169	0.075	0.014	1.023
Neuro-QOL Anxiety				-0.138	0.004	2.458
Neuro-QOL Fatigue	-0.330	.000	1.657			
Neuro-QOL General Cognition				0.140	0.000	1.467
Neuro-QOL Depression				-0.506	0.000	2.616
Self-Efficacy for Managing Chronic Disease Scale	0.274	.000	1.596	0.125	0.001	1.637
<b><u>ENVIRONMENT VARIABLES</u></b>						
Assistance	-0.83	.032	1.135			
Marital Status	0.097	0.11	1.117			
Neuro-QOL Stigma				0.078	0.031	1.438
<b><u>OCCUPATION VARIABLES</u></b>						
Affect on Daily Life	-0.117	.007	1.446			

### 3.5.3.1 Self-Reported General Health

P variables demonstrated the strongest association with SRH. Increasing age ( $\beta = -0.101$ ) and fatigue ( $\beta = -0.330$ ) were negatively associated with SRH. Self-efficacy ( $\beta = 0.274$ ) was positively associated with SRH.



Two E variables were associated with SRH. Greater need for assistance ( $\beta = -0.83$ ) was associated with lower levels of SRH. Being married or previously married ( $\beta = 0.097$ ) was positively associated with higher levels of SRH.

Of the four O variables, only one demonstrated a relationship to SRH. The question “how much do you feel that your neurological condition(s) affects your life,” was negatively associated ( $\beta = -0.117$ ) with lower SRH.

### **3.5.3.2 Self-Reported Mental Health**

Like SRH, P variables, in this case, age, self-efficacy, and cognition demonstrated the greatest influence on SRMH. In contrast to SRH, increasing age ( $\beta = 0.075$ ) was positively associated with SRMH. Self-efficacy ( $\beta = 0.125$ ) was positively associated with SRMH. General cognition ( $\beta = 0.140$ ) also demonstrated positive associations to SRMH while depression ( $\beta = -0.506$ ) and anxiety ( $\beta = -0.138$ ) negatively affected SRMH.

Stigma was the only E variable that demonstrated an association with SRMH, increasing stigma ( $\beta = 0.078$ ) was negatively associated with SRMH.

No O variables demonstrated a statistically significant relationship with SRMH.

## **3.6 DISCUSSION**

The aim of this study was to determine which PEO factors were associated with SRH and SRMH for adults living in Canada with a chronic neurological condition. Of this sample, 32.8% and 24.2% of respondents reported fair to poor levels of SRH and SRMH compared to 10.9% and 5.7% of the general Canadian population, respectively (Bray et al., 2014). Based on this sample, Canadians living with a chronic neurological condition have lower levels of SRH and SRMH than the general population.

This study identified that the person-level variables, depression, fatigue, and self-efficacy had the greatest influence on SRH and SRMH for people living with a chronic neurological condition. Anxiety also had a significant influence on SRMH. Frequent practice targets of rehabilitation therapy, upper extremity and lower extremity function, were not significantly associated with SRH or SRMH in this cohort. While it is possible these findings suggest that impairment reduction approaches related to the upper extremity and lower extremity function may not improve SRH and SRMH further research is required to investigate this relationship. This study focused on individuals living with a chronic neurological condition. There is some evidence in specific neurological conditions indicating that the factors associated with SRH and SRMH may change over time as the individual lives with the condition. (Algurén et al.; 2012; Lin et al., 2010; Van Mierlo et al., 2016).

Based on the results of this study, as outlined in the introduction, models of care that shift the emphasis from diagnosis to functional requirements may improve SRH and SRMH. More specifically, functional approaches integrating behavioural therapy-based interventions, such as problem-solving, goal setting, and education, with opportunities to develop performance mastery by focusing on small successes and providing positive feedback may improve SRH and SRMH for individuals living with a chronic neurological condition (Lau et al. 2020; Stevens et al., 2020).

Depression had the greatest influence on SRMH with higher levels of depression associated with lower SRMH. This result substantiates findings of previous studies focused on singular neurological conditions, that have also shown that depression is negatively associated with SRMH (Johnson et al., 2004; Lo et al., 2020; Shrag, 2006; Soh et al., 2011). Karatepe et al. (2011) postulated that depressive symptoms may influence SRMH directly through a negative

outlook thereby resulting in negative self-reports and poor coping strategies, which are negatively associated with SRMH (Sandstedt et al., 2016).

Depression has also been shown to indirectly influence SRMH through its relationship with other symptoms, particularly fatigue and sleep (Karatepe et al., 2011; Magistrale et al., 2015). Several researchers (Ghroubi et al. 2016; Nourbakhsh et al., 2016) have reported that depressive symptoms may be responsible for the presence of fatigue. However, this study did not replicate those findings. Fatigue was the person-level variable with the greatest influence on SRH only. Other research has found a similar relationship between fatigue and SRH (Berrigan et al., 2016). Schmidt and Jöstingmeyer, (2019) suggested that cognitive and physical fatigue are associated with distinct problems in daily functioning, which differentially impact daily life and SRH. Based on the results of this study, it is possible that individuals living with a neurological condition consider the impact of fatigue on their health from a physical perspective. Given that sleep and depression were not associated with SRH, it is also possible that fatigue is a result of nervous system pathology as opposed to those secondary causes related to comorbidity (Plow et al., 2020).

Cognitive impairment was also negatively associated with SRMH. In people having experienced traumatic brain injury (TBI), depression is known to negatively influence cognitive function (Chamelian & Feinstein, 2006). In their study examining the effect of cognitive impairment on the SRH in a TBI population, Gorgoraptis et al. (2019) expanded on that finding noting that cognitive impairment may be part of the process by which depression causes emotional problems affecting SRMH. The authors went on to state that successful treatment of depression in TBI may lead not only to the improvement of SRMH but also to improvement in cognitive function. Given the findings of this study, from a rehabilitation perspective, it would

seem prudent for rehabilitation professionals to screen for depressive symptoms and cognitive impairment with people living with a chronic neurological condition. Additionally, appropriate intervention for depression may result in an improvement in SRMH through a reduction in depressive symptoms and an improvement in cognitive function.

Self-efficacy was the factor with the greatest influence on both, SRH and SRMH. A recent study found that people living with neurological conditions use many strategies that frequently interact and complement one another to successfully manage their conditions (Auduly et al., 2020). Implementing these strategies through learning new behaviours and/or modifying one's lifestyle becomes a necessity. Self-efficacy is consistently shown to be a powerful factor to consider when predicting those that successfully manage these changes (Guicciardi et al., 2019; Jones & Riazi, 2011; van Mierlo et al., 2018).

Self-management interventions have been shown to improve self-efficacy (Jones & Riazi, 2011). Self-management interventions are designed to enable individuals to take an active part in managing their health and many are effective in improving the symptoms related to chronic neurological conditions (Lau et al., 2020; Plow et al., 2011). To effectively self-manage, individuals living with chronic neurological conditions must have knowledge of their physical condition and how to prevent complications or control them if they do occur (van Diemen et al., 2018). While self-management of a neurological condition may be understood as disease-specific, the results of this research identified several variables common to many neurological conditions that may improve SRH and SRMH through self-management interventions. For example, greater self-efficacy is associated with less fatigue and depression (Brunton et al., 2019; Graziolo et al., 2019; Hughes et al., 2015; Penner & Paul, 2017), two variables negatively associated with SRH and SRMH, respectively, in this sample. Recent reviews of self-

management interventions (Kidd et al., 2017; Lau et al., 2020) identified a positive impact on depression, fatigue, and self-efficacy of individuals living with chronic neurological conditions. Previously mentioned as the model of a functional approach, positive outcomes were associated in studies that employed cognitive behavioural therapy-based interventions employing elements of problem-solving, goal setting, exercise, and education.

In this study, the need for assistance had a small, negative association with SRH. Although classified as an environmental factor, the need for assistance may also be a marker for greater person-level impairment. Other studies have found similar outcomes (Hahn et al., 2018; Hopman et al., 2007). This finding does not imply that assistance does not enhance SRH. A more plausible explanation is that those with greater impairments and disability are more likely to require some form of assistance. The previously mentioned research found that those who receive assistance had greater physical impairments are in later stages of the disease, are older, have less education, and poorer functional and cognitive skills (Hahn et al., 2018). Consequently, as many of these variables are not modifiable, a further argument can be made for a functional approach. This finding may also lend further support for self-management interventions to encourage individuals to take an active role in managing their health as they experience greater impairments and disability.

A surprising finding of this study was the influence of stigma on SRMH; greater levels of stigma were associated with better levels of SRMH. This contradicts previous research that shows that stigma is associated with lower self-reported health, greater physical impairments, lower self-efficacy, and depression (Ma et al., 2016; Victorson et l., 2014). This discrepancy may exist for a couple of reasons. It may be due to personal reactions to stigma. Corrigan and Watson (2002) stated that stigma may result in low levels of self-esteem and self-efficacy for some while

others may be energized. A second explanation may be related to the distribution of responses on the Neuro-QoL. The Stigma Scale had a greater frequency of responses at the low end of the variable, suggestive of less stigma. Therefore, this cohort may experience a relatively lower level of stigma.

### **3.6 LIMITATIONS**

This study has some limitations. The sample for this study used a previously collected data set for a secondary analysis. This data set used convenience sampling and a specific set of measures, which can potentially limit information and generalization. Furthermore, this data was collected almost a decade ago. Future research could explore similar questions using present data and other variables that might be of significance for this population. This study used single-item measures of SRH and SRMH to explore the research questions. Future research could also explore the same questions comparing multiple measures of SRH and SRMH such as the SF-36.

While this sample of Canadians living with a chronic neurological condition reported lower levels of SRH and SRMH than the general population, this cohort also reported a greater frequency of responses at the high end of the two Neuro-QoL participation variables, suggestive of relatively higher function. Although the respondents in this study reported relatively lower health, it was possible that they were relatively able to participate in and were satisfied with their social roles and activities. Future research could examine the relationship between SRH, SRMH, and occupation variables in a cohort with a lower level of ability and satisfaction in social roles and activities.

### **3.8 CONCLUSION**

Canadians living with a chronic neurological condition report significantly lower levels of SRH and SRMH than the general population. This study has identified several rehabilitation factors to improve SRH and SRMH in individuals living with a chronic neurological condition. This study identified self-efficacy, fatigue, and depression as factors associated with SRH and SRMH, all of which may be improved through self-management interventions.

### **3.9 DECLARATION OF INTEREST**

No potential competing interest was reported by the authors.

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## CHAPTER 4 ADDITIONAL ANALYSIS

### 4.1 INTRODUCTION

As outlined in the previous chapter, ordinal regression and backward OLS linear regression techniques were explored for the final model with the latter chosen for the final analysis. This chapter describes the ordinal regression process undertaken for this study and the rationale for the decision to use OLS linear regression for the final model.

### 4.2 ORDINAL REGRESSION

Ordinal regression analysis is suitable when the dependent variable is of ordinal nature; that is, the outcome variable is ordered, and has more than two levels (Bourne, 2009). It estimates the average odds ratios of all possible aspects of the response variable, which are assumed to be equal (Norušis, 2012). Further, assumptions of the ordinal regression model are that one or more of the independent variables is either continuous, categorical, or ordinal and do not demonstrate multi-collinearity (Field, 2018). The assumptions of no multi-collinearity and the description of independent variables related to this study were previously described in Chapter 3.

As a Likert type scale, SRH is assumed to produce responses that are ordered from poor to excellent on a five-point scale. Prior research has treated SRH as a dependent variable in several ways. It has been dichotomized into good health or less (Manor et al., 2000), maintained as an ordered, categorical variable (Joffer et al., 2019), or considered a continuous interval variable (Garbarski et al., 2015; Jürges et al., 2008; Meng et al., 2014). When SRH is dichotomized and logistic regression has been used, researchers are faced with the dilemma of making an arbitrary choice as to where the variable should be dichotomized, and collapsing the variable may result in the loss of information (Norris et al., 2006). There is the added issue of whether imposing this

change on the dependent variable may create biases in the analysis due to the subjectivity of individual choice (Bourne, 2009). Accordingly, researchers have suggested that SRH should remain a Likert scale measure or be interpreted as a continuous variable rather than dichotomizing the variable (Mackenback et al., 1994; Manderbacka et al., 1998; Manor et al., 2000). For purposes of comparison with Table 2, the frequencies for the dependant variables dichotomized into less than good and good or better SRH and SRMH are presented in Table 7. The frequencies indicate dichotomizing the dependent variables led to a skewed distribution towards good or better health.

**Table 7 – Frequency Statistics for Dichotomized Dependent Variables**

<b>Dependent Variables</b>	<b>Frequency</b>	<b>Percent</b>
<b>Self-Rated General Health (n = 744)</b>		
Less than Good	244	32.8
Good or Better	500	67.2
<b>Self-Rated Mental Health (n = 735)</b>		
Less than Good	179	24.4
Good or Better	556	75.6

While the arguments presented above discourage dichotomizing the dependent variable and therefore using logistic regression, the choice between using ordinal regression model or OLS linear regression is also not straightforward. Scott et al. (1997) argue that ordinal regression modeling avoids the unjustified assumption of equal differences between categories that occurs when ordinal data are treated as continuous. In opposition to Scott et al. (1997), Manderbacka et al. (1998) found that SRH forms a continuum when risk factors and ill health are considered. One suggestion is that doing both an OLS linear regression model and an ordinal regression

model may produce the most comprehensive interpretation of the data (Norris et al., 2006). This was the process followed for this research project.

### 4.3 STATISTICAL ANALYSIS

The statistical procedures prior to conducting the ordinal regression were previously discussed in Chapter 3. Subsequent to the bivariate analysis, all independent variables that met the inclusion criteria were entered simultaneously into the backward ordinal regression model for each dependent variable. Successive models excluded the least significant variable until all remaining variables demonstrated significance ( $p \leq 0.05$ ). (Field, 2018). This process was repeated for both dependent variables, SRH and SRMH models.

### 4.4 RESULTS

#### 4.4.1 Self-Rated Health

The final ordinal regression model for SRH included six independent variables significantly associated with SRH at  $p < 0.05$  that were (Table 8). They are, in alphabetical order: Ages 27-65, Fatigue, the question “How much do you feel that your condition(s) affect/affects your life? Not at all to a little bit”, No Assistance and Self-efficacy.

**Table 8: SRH Ordinal Regression Results**

Variable	B (SE)	Lower	Odds Ratio	Upper
<i>Ages 27-55</i>	.431 (.199)	.041	1.539	.822
<i>Ages 55-65</i>	.677 (.223)	.239	1.967	1.115
<i>Fatigue</i>	-.083 (.011)	-.104	.920	-.062
<i>How much do you feel that your condition(s) affect/affects your life? Not at all to a little bit</i>	.716 (.257)	0.212	2.046	1.220

<b>Variable</b>	<b>B (SE)</b>	<b>Lower</b>	<b>Odds Ratio</b>	<b>Upper</b>
<i>No Assistance</i>	.361 (.149)	.069	1.435	.653
<i>Self-efficacy</i>	0.306 (0.42)	.224	1.358	.388

### *Age*

For those aged 27-55, there was a predicted increase of .431 in the log odds of a respondent having better SRH. The odds of having better SRH was 1.539 for those between the ages 27-55 compared to those over 65. For those aged 55-65, there was a predicted increase of .677 in the log odds of a respondent having better SRH. The odds of having better SRH was 1.967 for those between the ages 55-65 compared to those over 65.

### *Fatigue*

For every one unit increase in Fatigue, there was a predicted decrease of .083 in the log odds of a respondent having better SRH. The odds ratio indicates that the odds of having better SRH increases by a factor of .920 for every one unit increase in Fatigue. Given that the odds ratio is < 1, this indicates a decreasing probability of having better SRH as scores increase on Fatigue.

*“How much do you feel that your condition(s) affect/affects your life? Not at all to a little bit”*

For those feeling that their condition had no to little effect on their daily life, there was a predicted increase of .716 in the log odds of a respondent having better SRH. The odds of having better SRH was 2.046 compared to those with feeling that their condition has some effect on their daily life.

### *No Assistance*

For those with no assistance, there was a predicted increase of .361 in the log odds of a respondent having better SRH. The odds of having better SRH was 1.435 compared to those with assistance.

*Self-efficacy*

For every one unit increase in the Self-Efficacy score, there was a predicted increase of .306 in the log odds of a respondent having better SRH. The odds ratio indicates that the odds of having better SRH increases by a factor of 1.358 for every one unit increase on the self-efficacy score.

*Model Fit*

The likelihood ratio chi-square test was used to test whether there was a significant improvement in the fit of the Final model relative to the Intercept only model. In this case, there was a significant improvement in the fit of the Final model over the null model (*Table 9*).

**Table 9: Model Fitting Information**

<b>Model</b>	<b>-2 Log Likelihood</b>	<b>Chi-Square</b>	<b>df</b>	<b>Sig.</b>
Intercept Only	2040.26			
Final	1697.34	342.93	9	.000

Nagelkerke’s pseudo R<sup>2</sup> for the final model is presented as a measure of the model’s explanatory capacity in *Table 10*. Nagelkerke’s pseudo R<sup>2</sup> for the model was 0.400, which implied that the model’s explanatory capacity was 40.0%.

**Table 10: SRH Pseudo R-Square**

Cox and Snell	.377
Nagelkerke	.400
McFadden	.167

Pearson and Deviance goodness-of-fit measures had contrary results (*Table 11*). The Pearson goodness-of-fit statistic indicated significance implying poor model fit with the data. Non-significant test results are indicators that the model fits the data well (Field, 2018). However, 79.7% of the cells (i.e. dependent variable levels by observed combinations of predictor variables) had zero frequencies. With so many empty cells neither statistic provides a dependable goodness-of-fit test (Norušis, 2012). There are likely to be many empty cells if your independent variables are continuous or have numerous categories.

**Table 11: SRH Goodness-of-Fit**

	<b>Chi-Square</b>	<b>df</b>	<b>Sig.</b>
<b>Pearson</b>	3815.43	2815	.000
<b>Deviance</b>	1683.48	2815	1.000

The test of parallel lines revealed a significant Chi<sup>2</sup> ( $p=.005$ ) which indicated that the assumption of proportional odds was not satisfied (*Table 12*).

**Table 12: Test of Parallel Lines**

<b>Model</b>	<b>-2 Log Likelihood</b>	<b>Chi-Square</b>	<b>df</b>	<b>Sig.</b>
Null Hypothesis	1697.34			
General	1647.78	49.56	27	.005

#### 4.4.2 Self-Rated Mental Health

The final ordinal regression model for SRMH revealed nine statistically significant independent variables ( $p < 0.05$ ) associated with SRMH (*Table 13*): They are, in alphabetical order: Ages 26 or less, Anxiety, Depression, Fatigue, General Cognition, No Comorbid Conditions, Self-efficacy, Sleep Disturbance, and Stigma.

**Table 13: SRMH Ordinal Regression Results**

<b>Variable</b>	<b>b (SE)</b>	<b>Lower</b>	<b>Odds Ratio</b>	<b>Upper</b>
<i>Age Grouping &lt;= 26</i>	-1.029 (.344)	-1.703	.357	-.356
<i>Anxiety</i>	-.029 (.014)	-.056	.971	-.002
<i>Depression</i>	-.145 (.015)	-.173	.865	-.116
<i>Fatigue</i>	.039 (.013)	.013	1.039	.064
<i>General Cognition</i>	.050 (.009)	.031	1.051	.068
<i>No Comorbid Conditions</i>	.355 (.151)	.058	1.426	.651
<i>Self-efficacy</i>	0.197 (.043)	.112	1.218	.282
<i>Sleep Disturbance</i>	-0.036 (.013)	-.061	.964	-.011
<i>Stigma</i>	.026 (.011)	.003	1.026	.048

### *Age*

For those aged 26 or younger, there was a predicted decrease of 1.029 in the log odds of a respondent having better SRMH. The odds of having better SRMH was .357 for those between the ages 26 or younger compared to those over 65. Given that the odds ratio is < 1, this indicates a decreasing probability of having better SRMH in this age category.

### *Anxiety*

For every one unit increase in the anxiety variable, there was a predicted decrease of .029 in the log odds of a respondent having better SRMH. The odds ratio indicates that the odds of having better SRMH increases by a factor of .971 for every one unit increase on anxiety. Given that the odds ratio is < 1, this indicates a decreasing probability of having better SRMH as scores increase on Anxiety.

### *Depression*

For every one unit increase in depression, there was a predicted decrease of .145 in the log odds of a respondent having better SRMH. The odds ratio indicates that the odds of having better SRMH increases by a factor of .865 for every one unit increase on depression. Given that the odds ratio is  $< 1$ , this indicates a decreasing probability of having better SRMH as scores increase on depression.

### *Fatigue*

For every one unit increase in fatigue, there was a predicted decrease of .039 in the log odds of a respondent having better SRMH. The odds ratio indicates that the odds of having better SRMH increases by a factor of 1.039 for every one unit increase in fatigue.

### *General Cognition*

For every one unit increase in general cognition score there was a predicted increase of .031 in the log odds of a respondent having better SRMH. The odds ratio indicates that the odds of having better SRMH increases by a factor of 1.051 for every one unit increase in the general cognition score.

### *No Comorbid Conditions*

For those with no comorbid conditions, there was a predicted increase of .355 in the log odds of a respondent having better SRMH. The odds of having better SRMH was 1.426 compared to those with a comorbid condition.

### *Self-efficacy*

For every one unit increase in the self-efficacy score, there was a predicted increase of .197 in the log odds of a respondent having better SRMH. The odds ratio indicates that the odds of



having better SRMH increases by a factor of 1.218 for every one unit increase in the self-efficacy score.

*Sleep Disturbance*

For every one unit increase in the sleep disturbance score, there was a predicted decrease of .036 in the log odds of a respondent having better SRMH. The odds ratio indicates that the odds of having better SRMH increases by a factor of .964 for every one unit increase on sleep disturbance. Given that the odds ratio is < 1, this indicates a decreasing probability of having better SRMH as scores increase on Sleep Disturbance.

*Stigma*

For every one unit increase in the stigma score there was a predicted increase of .026 in the log odds of a respondent having better SRMH. The odds ratio indicates that the odds of having better SRMH increases by a factor of 1.026 for every one unit increase in the stigma score.

*Model Fit*

As with SRMH the likelihood ratio chi-square test indicated there was a significant improvement in fit of the Final model over the null model (*Table 14*).

**Table 14: SRMH Model Fitting Information**

<b>Model</b>	<b>-2 Log Likelihood</b>	<b>Chi-Square</b>	<b>df</b>	<b>Sig.</b>
Intercept Only	2169.30			
Final	1629.11	540.19	11	.000

Nagelkerke’s pseudo R<sup>2</sup> for the final model was 0.557, which implied the model’s explanatory capacity was 55.7% (*Table 15*).

**Table 15: SRH Pseudo R-Square**

Cox and Snell	.530
Nagelkerke	.557
McFadden	.249

Contrary to SRH, Pearson and Deviance goodness-of-fit measures were both insignificant implying good model fit (*Table 16*). Like SRH, there were 80.0% of the cells had zero frequencies.

**Table 16: SRMH Goodness-of-Fit**

	<b>Chi-Square</b>	<b>df</b>	<b>Sig.</b>
<b>Pearson</b>	2411.04	2845	1.000
<b>Deviance</b>	1629.11	2845	1.000

Contrary to SRH, the test of parallel lines for SRMH revealed an insignificant  $\chi^2$  ( $p=.005$ ) indicating the assumption of proportional odds was satisfied (*Table 17*).

**Table 17: Test of Parallel Lines**

<b>Model</b>	<b>-2 Log Likelihood</b>	<b>Chi-Square</b>	<b>df</b>	<b>Sig.</b>
Null Hypothesis	1629.11			
General	1587.23	41.86	33	.138

## 4.5 DISCUSSION

The ordinal regression model for SRH resulted in several similarities to the OLS linear regression model. In summary, respondents were more likely to have better SRH if they were between the ages of 27 and 56, had a neurological condition that had little to no effect on their daily lives, needed no assistance, and had higher self-efficacy. Respondents with higher levels of fatigue were more likely to report lower SRH.

In comparison to the OLS linear regression model, the ordinal regression model for SRMH included several additional variables. Respondents were more likely to have better

SRMH if they had higher general cognition, no comorbid conditions, higher self-efficacy, and more stigma. Respondents aged 26 or younger, higher scores on anxiety, depression, fatigue and sleep disturbance were more likely to report lower levels of SRH. The unexpected increase in SRMH with more stigma was consistent with the findings of the OLS linear regression. Reasons for this finding were discussed in Chapter 3.

While the ordinal regression model offers meaningful clinical differences related to the dependent and independent variables, the assumptions related to the model were not held for SRH. The goodness-of-fit statistic implied poor model fit and the test of parallel lines indicated that the assumption of proportional odds was not satisfied. Therefore, test statistics with such models are unreliable. Proportional odds assumption is a requirement for the application of the ordinal logistic regression model for an ordered categorical variable (Liang et al., 2020). As discussed in the results, 79.7% and 80% of cells associated with SRH and SRMH, respectively, produced zero frequencies. Because of the empty cells, there is uncertainty as to whether the data fit a chi-square distribution, possibly leading to inaccurate significance values (Spais & Vasileiou, 2006).

Given the similarities in outputs of both models and the questionable validity of the final ordinal regression model, the OLS linear regression model was chosen for the final analysis. Given the similarities in outputs for both types of analysis and that SRMH met the thresholds, it could be argued that the ordinal model was an equally appropriate choice. However, as stated previously, ordinal regression models for both dependent variables had a significant percentage of empty cells. It's worth noting that the dependent variables and several independent variables were recoded to reduce the number of empty cells. Reducing the dependent variables to three categories for the ordinal regression reduced the number of empty cells to 69% and resulted in

better distribution of the data. However, 69% empty cells still create uncertainty related to the results.

## CHAPTER 5 DISCUSSION

The objective of this study was to determine the PEO factors associated with SRH and SRMH for adults living in Canada with a chronic neurological condition. Contrary to expectations, only one measure of occupation was associated with one of the dependent variables, SRH. The findings of this study have several possible implications for clinical practice and future research.

### 5.1 IMPLICATIONS FOR CLINICAL PRACTICE

The motivation for this thesis came from a desire to test two related questions with implications for theory and clinical practice. The first question is related to the theory that occupation is associated with health. This theory is a fundamental belief of occupational therapy (Townsend & Polatajko, 2007; Wilcock, 2007). Occupational therapists believe that health is improved through participation in meaningful activities. Therefore, with a focus of clinical practice on enabling occupations, occupational therapists believe that health will be improved. This theory is not supported by the results of this study. In this group of Canadians living with a chronic neurological condition ability to participate and satisfaction with social roles were not associated with SRH and SRMH. Therefore, it is possible that enabling occupation may not improve SRH or SRMH. However, several alternatives are possible. One, the inverse may be true. Health is also thought of as a resource for living as opposed to an outcome (Townsend & Polatajko, 2007). Other research on a subset of the cohort used for this study found an association between SRH and participation (Warner et al., 2017), thus providing some support for this assertion. Secondly, there were limited occupation-level variables relative to person-level variables. Furthermore, no additional or specific analysis was performed on occupation variables.

The second question of interest for undertaking this study was related to clinical practice. In addition to enabling occupation, there is a tendency in clinical practice, across several rehabilitation professions, to focus on impairment reduction of person-level factors as a means of improving SRH and SRMH. Specifically, addressing impairment associated with upper extremity and lower extremity function are frequent outcomes in clinical practice. Reduction of impairment associated with person-level factors may be outcomes that enable occupation, or it may be the sole may be the outcome of interest. That is, limitations in lower extremity or upper extremity function may be identified during the assessment with an impairment reduction approach taken to restore some motor function or prevent further loss of function. Because neurological conditions are, for the most part, managed, not cured, it was felt that this population represented an opportunity to test this clinical practice. The results of this study imply that upper or lower extremity function is not positively associated with SRH and SRMH.

Clinically, this study supports addressing the clinically modifiable factors of anxiety, fatigue, depression, and self-efficacy, to improve SRH and SRMH for individuals living with a chronic neurological condition. As discussed in Chapter 3, self-management interventions have been shown to improve self-efficacy (Jones & Riazi, 2011). Self-management interventions are designed to enable individuals to take an active part in managing their health and are effective in improving some of the symptoms related to chronic neurological conditions (Lau et al., 2020; Plow et al., 2011).

Several recent reviews of self-management interventions for improving anxiety, depression, fatigue, and self-efficacy have identified characteristics of interventions associated with positive outcomes for individuals living with chronic neurological conditions (Kidd et al., 2017; Lau et al., 2020). Kidd et al. (2017) conducted a systematic review to examine the

effectiveness of self-management interventions on improving depression and anxiety in people living with multiple sclerosis. The researchers found that cognitive behavioural therapy and behavioural components such as goal setting were most associated with improvements in depression and anxiety. However, the authors reported that the results were limited by methodological issues and insufficient evidence to draw clear conclusions. Lau et al. (2020) reviewed studies associated with the effectiveness of interventions for improving anxiety, depression, and fatigue across a range of neurological conditions, including epilepsy, traumatic brain injury, multiple sclerosis, and spinal cord injury. The authors found positive outcomes associated with anxiety, depression, fatigue, and self-efficacy across studies that employed cognitive behavioural therapy-based interventions. Specifically, problem-solving, goal setting, exercise, and education were key elements of successful cognitive behavioural therapy-based interventions. The authors also reported that digital self-management interventions are effective in improving depression, anxiety, fatigue, and self-efficacy among people with neurological disorders. As with the review by Kidd et al., Lau et al. recommended some caution due to methodological issues. For example, control conditions were waitlist or no intervention. Most studies also did not blind the participants and research personnel which could affect the risk of bias. Nevertheless, these studies provide some direction for rehabilitation professionals in addressing these factors to improve SRH and SRMH for individuals living with chronic neurological conditions.

## **5.2 IMPLICATIONS FOR FUTURE RESEARCH**

This study was completed with a cohort of Canadians living with a chronic neurological condition. There is some evidence in specific conditions indicating that the factors associated

with SRH and SRMH may change over time as the individual lives with the condition. In their study of 99 stroke patients, Algurén et al. (2012) found that person and occupation factors were associated with SRH at three months post-stroke. However, by one-year post, environment factors were more significantly related. Van Mierlo et al. (2016) found that SRH also improved over the first six months post-stroke. Similar findings exist for individuals post brain injury (Lin et al., 2010). Thus, there may be changes in factors and SRH following the initial diagnosis or onset of the disease process.

Future research should explore these differences over time in a cohort of individuals living with a neurological condition. This research has not been conducted on a group of individuals living with a variety of neurological conditions. The findings of this research would guide rehabilitation professionals in providing the appropriate care for individuals at each stage of the condition.

Future research could also explore the relationship of occupational performance with SRH and SRMH using the PEO Model. This project used the PEO Model to organize variables to determine the factors associated with SRH and SRMH for adults living in Canada with a chronic neurological condition without specific consideration of individual factors. Again, using the PEO Model, future research could determine if participation in daily occupations is positively associated with SRH and SRMH in people living with a chronic neurological condition.

As stated in the literature review, there may not be a single measure suitable for all purposes or as a measure of “true” health (Garbarski, 2016). This study used single-item measures of SRH and SRMH. Future research could compare SRH and SRMH using preference-based measures such as the HUI3 and SF-6D in the same neurological population. Comparisons of health measures are necessary for selecting the most sensitive measure of the health construct



of interest (Fisk et al., 2005). Differences in the way instruments define, explain, and value health affect the interpretation and meaning associated with the results (Abel et al. 2017). Furthermore, results across different measures are not necessarily interchangeable (Abel et al., 2017; Fisk et al., 2005; Pickard et al., 2005). Thus, different measures may produce different associations between the instrument and the independent variables.

Finally, as outlined in the introduction, a purpose of studying the factors associated with SRH and SRMH across a range of neurological populations was to develop effective rehabilitation interventions. Future research could explore self-management strategies to improve anxiety, depression, fatigue, and self-efficacy across neurological populations. As discussed above, there is evidence to suggest that self-management interventions are associated with positive outcomes for these factors. However, the methodological issues associated with existing studies imply some caution. Future studies should address these methodological issues such as appropriate control groups and blinding.

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