

**Participation Outcomes In Rehabilitation For Individuals With Chronic
Neurological Conditions**

By

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Abstract

The purpose of this research project was to identify personal and environmental factors that facilitate both ability to participate in life roles and satisfaction with that participation, for people living with chronic neurological conditions. Contributions of self-efficacy and patient activation to participation were also examined.

The results of this secondary analysis confirmed previous work that demonstrates that participation is multi-factorial. Using multiple regression techniques, the final models explained more of the variation in ability than satisfaction. The significant variables in the final models were impairment, fatigue, stigma and either self-efficacy or patient activation. For the ability to participate models only, support was a significant variable. Neither self-efficacy nor patient activation was more predictive of participation.

For clinicians working with this population, re-examination of the current impairment reduction focus is warranted. More comprehensive approaches that support the complexities of daily living for these individuals are indicated. Several factors for rehabilitation intervention were implicated.

List Of Abbreviations and Symbols Used

Ability – Ability to Participate in Social Roles and Activities

ANOVAs – Analysis of variance

β - (Beta) Regression coefficient

CIHI – Canadian Institute for Health Information

HRQOL – Health Related Quality of Life

HUI – Health Utilities Index

ICF – International Classification of Disability and Function

LINC – Living with the everyday impact of a neurological condition (study)

MCS – Mental Composite Score (SF-36)

MH – Mental Health

MS – Multiple Sclerosis

MSE – Mean Squared Error

Nbs – Norm-based score

NeuroQoL – Neurological Quality of Life (Scales)

NHCC – Neurological Health Charities of Canada

NIH – National Institutes for Health

PAM – Patient Activation Measure

PAM-13 – Patient Activation Measure (13 item)

PCS – Physical Composite Score (SF-36)

PHAC – Public Health Agency of Canada

PIH – Partners in Health

Satisfaction – Satisfaction with Participation in Social Roles and Activities

SE – Self-efficacy

SEMCD -6-item Self-Efficacy for Managing Chronic Disease Scale

SF-36 – Medical Outcomes Scale, short form

Sig diff – significant difference

SLNCC – Survey on Living with Neurological Conditions in Canada

UN – United Nations

WHO – World Health Organization

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Chapter 1 Introduction

1.1 Project Outline

The current research sought to improve our knowledge of the factors that influence participation for individuals living in Canada with chronic neurological conditions. Chapter one offers an introduction to the research project, and outlines the need for enhancing our understanding of participation for this population. Chapter two reviews and summarizes the current literature with regard to rehabilitation for chronic conditions, participation, self-efficacy, and patient activation. Chapter three provides a description of methods and analysis, and Chapter four follows with results. Chapter five concludes with discussion, limitations and key clinical messages resulting from the findings.

1.2 Scope Of Need

Neurological conditions are a leading cause of disability in Canada (CIHI, 2007; PHAC, 2014). The prevalence of these conditions is expected to rise over the coming decades with concomitant increases in healthcare costs (PHAC, 2014). In addition to systemic costs, there are personal costs in lost productivity, decreased life expectancy and decreased quality of life (PHAC, 2014). Neurological conditions often have wide-ranging functional effects including changes in mobility, cognition, behavior, affect, and self-care. These impacts are chronic and can be progressive or episodic (PHAC, 2014). For individuals living with chronic conditions, these contribute to multiple challenges including “loss of social and vocational roles,

permanent changes in lifestyle, threats to self-image and self-esteem, disruption to normal life transitions, uncertain and unpredictable futures, and decreasing resources” (White et al., 1992, p.211). Needs are not static for individuals with chronic conditions; as the condition progresses, changes or fluctuates, it necessitates repeated adaptations to lifestyle, roles and activities.

The current medical system was created and structured to deal with the urgent medical needs of people with acute illness and injury, and has been slow to adapt to the long term and substantially different needs of those with a chronic condition (Bourbeau, 2008; Stav et al., 2012; Wagner et al., 2001). As the population of individuals with chronic conditions increases, researchers and theorists have turned attention to the needs of this group, proposing new models of care, including the Chronic Care Model (Wagner et al., 2001), the Expanded Chronic Care Model (Barr et al., 2003) and the Chronic Care Model for Neurological Conditions (Jaglal et al., 2014). These models of care have been suggested to address the less acute, and more often, community-based needs of those with chronic conditions. Significant and consistent in these models are a client-centred focus, and promotion of engaged, activated clients, with knowledge and skills to manage their symptoms, medications and life demands relative to the condition.

Consistent with the chronic care models identified above, engaging these individuals in self-management approaches is a strategy to address the increasing monetary and

societal costs associated with an increased prevalence of chronic conditions (Townsend, 2011). Further, self-management strategies are beneficial in addressing the needs of individuals with chronic conditions who have to cope with “...the physical, psychological and social demands of their illness without much help or support from medical care“ (Wagner et al., 2001; p.65).

There is disagreement about what comprises a self-management program (Barlow et al., 2002; Chodosh et al., 2005), however this approach encompasses multiple aspects, including knowledge of the condition, management of symptoms, and lifestyle adaptations (Barlow et al., 2002). Research has demonstrated that self-management programs have been effective at improving medical outcomes in some chronic conditions (Barlow et al., 2002; Chodosh et al., 2005; Kennedy et al., 2007; Lorig and Holman, 2003), however, little is known about the mechanisms that support successful self-management outcomes. In their concept review, Auduly and colleagues (2016) identified two perspectives evident in the literature; one identifying self-management as it relates to adherence to medical advice to manage medications and symptoms, the other more encompassing of additional supports and strategies to address living well with the condition. Much of the existing literature has been largely focused on the former perspective, examining biomedical and system outcomes rather than the outcomes, such as participation, that are of import to the lives and choices of individual clients (Adamit et al., 2015; Cott et al., 2007; Frosch and Elwyn, 2010).

1.3 Importance Of Participation

The United Nations 'Convention on the Rights of Persons with Disabilities' (Article 26) calls for rehabilitation efforts to "...enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life" (WHO 2011, p.95). Research has shown that participation is important to clients (Anaby et al., 2011; Blömer et al., 2015; Fairhall et al., 2011; Robison et al., 2009), and that loss of participation and activity results in decreased life satisfaction (Anaby et al., 2011; Blömer et al., 2015) and lower well-being and quality of life (Adamit et al., 2015, Anaby et al., 2011; Freedman et al., 2011; Robison et al., 200). As described by Wilkie et al. (2007): "How people function in the context of their daily lives may be of more concern to them than actual impairments or difficulties with individual tasks" (Wilkie et al., 2007, p.1147).

As outlined in the 'International Classification of Functioning, Disability and Health (ICF)', The World Health Organization identifies participation as an essential component of human health and well-being and promotes full inclusion and participation in all aspects of life for all humans (WHO, 2011). Participation is vital to the health and well-being of individuals and society and enables us to "...acquire skills and competencies, connect with others and our communities, and find purpose and meaning in life" (Law, 2002, p640).

Participation in life roles is a primary goal of rehabilitation (Law, 2002; Zhang et al., 2015), and has sometimes been used as an outcome measure for self-management programs (Augustine et al., 2011; Hibbard et al., 2007). Rehabilitation treatment ultimately aims to restore a person's participation in society, despite persistent sequelae of illness, such as impairments and disabilities (Cardol et al., 2002). However there exists a disconnect, in that many of the measures used by clinicians in neuro-rehabilitation continue to be impairment based, while clinician interventions are often purportedly focused on enhancing participation and facilitating return to life roles (Anaby et al., 2011). If specific factors that enhance participation can be identified, interventions and outcome measures could be improved to more precisely target these factors.

Because participation is a key outcome variable, both important to individuals and a benchmark of successful rehabilitation, it is a fundamental concept to explore. Identifying factors that enhance participation, and exploring how self-efficacy and patient activation might be linked with successful participation, could improve knowledge of mechanisms for change and provide direction for professionals working with adults with chronic neurological conditions. Clients must make ongoing decisions about their relative abilities, their roles and how to best manage the impacts of chronic neurological conditions. To develop an understanding of this multi-layered relationship requires a "...complex, grounded, and nuanced body of knowledge that will illuminate individual experience in chronic illness self-care decision making within a context of common patterns and themes" (Thorne et al.,

2003, p.1338). If clients can be provided skills and knowledge to improve participation, they may lead more complete lives, experiencing greater well-being and community participation, while potentially resulting in health care savings, as clients are more active and engaged in life roles.

This project examined components that might support participation in life roles for those living with chronic neurological conditions. Specifically investigated were the personal and environmental variables associated with participation, and whether self-efficacy or patient activation further improve participation outcomes.

Characterization of these relationships may enable targeted rehabilitation efforts to promote factors that support participation and ultimately improve long-term well-being and life satisfaction. Through identification of rehabilitation targets, researchers and clinicians can also potentially streamline their use of intervention measurement tools and create consistency, allowing greater comparison of results.

Chapter 2 Literature Review

2.1 Defining and Measuring Participation

With the introduction of the World Health Organization (WHO) – International Classification of Functioning, Disability and Health (ICF), a standard framework and language for describing the components of health was proposed. In this framework, participation is identified as one of four important domains of function, recognizing the importance of participation to health and well-being, and a key component of whole person function. However, despite the opportunity for consistent language, the vague definition of participation (‘involvement in a life situation’) and the unclear distinction between activity and participation continues to pose challenges for researchers (Badley, 2008; Davis et al., 2012; Dijkers 2010; Magasi and Post, 2010; Mallinson and Hammel, 2010; Resnick and Plow, 2009; Salter et al., 2005).

Currently there exists no consensus regarding how successful participation should be defined, or what indicators should be measured (Cardol et al., 2002; Eriksson et al., 2013; Fallahpour et al., 2011; Gadidi et al., 2011; Hammel et al., 2006; Hammel et al., 2008; Heinemann et al., 2010; Kessler and Egan, 2012; Law, 2002; Noureau and Boschen, 2010; Salter et al., 2005; Teasell et al., 2012; Warner et al., 2015; Whiteneck and Dijkers, 2009; Woodman et al., 2014). “Participation instruments are not equivalent because, even when linked to a single ICF code, items represent different aspects of a dimension” (Magasi and Post, 2010, p.S26). Research that focuses on participation is typically conceptually defined closer to performance

measures or 'capacity to perform' (Hammel et al., 2006). Researchers have examined physical activity as participation (Ashe et al., 2007; Gow et al., 2012), social engagement as participation (Berges et al., 2012; Desrosier et al., 2005; Gignac et al., 2012; Gilmour 2012; Hirschberg, 2012; Woodman et al., 2014), labour force participation (Baanders et al., 2002; Boot et al., 2008; Rijken et al., 2013) and frequency of activity (Blomer et al., 2015). Some research has examined participation, while other papers have examined its counter, participation restriction or activity limitation (Cardol et al., 2002; Davis et al., 2012; Fairhall et al., 2011; Goodridge et al., 2011). Additional work has identified changes in participation with lifespan (Desrosier et al., 2005). The lack of consensus means that what is measured depends on the goal of the research or program.

Although there is no clear definition, research is consistent in supporting the measurement of multiple components of participation. Participation does not occur in isolation; numerous personal, contextual and environmental factors influence the type and choice of activity (Biouffloux et al., 2011). It is clear that participation is complex and may be influenced by a myriad of factors including perceptions about the importance of roles, self-evaluations of limitations, and satisfaction with role performance (Gignac et al., 2013). Gignac and colleagues (2013) identify that these may change with age and/or with health, suggesting that variables other than simply diagnosis are important to understanding perceptions of role limitations. An assumption of uni-dimensionality is unlikely to capture the concept of participation,

as it changes within and among individuals, with different cultures, interests and settings (Whiteneck and Dijkers, 2009).

Participation reflects not only engagement in a situation, but the meaning and satisfaction associated with that engagement (Hammel et al., 2008). Literature concerning the conceptualization of participation stresses aspects such as the subjective experience and the individual perspective, including meaningfulness and satisfaction, as being important considerations when assessing participation (Fallahpour et al., 2011; Hammel et al., 2008; Noreau and Boschen, 2010). In a population of older adults with chronic conditions, Anaby et al. (2011) found that the number of chronic conditions, availability of social support, and *satisfaction with participation* were important contributors to well-being, whereas *accomplishment of participation* did not play as significant a role in the model.

Assessments of participation that include subjective components, such as satisfaction, are able to reflect the perspective of the individual rather than components based on a clinician's perspective (Brown, 2010). Examinations of participation should thus include both performance and satisfaction components, and represent a personal evaluation of successful participation relative to roles that the individual determines to be important and meaningful. "A comprehensive approach to assessing participation should not rely simply on counting people or activities or determining the degree of difficulty or needed assistance without taking into account the values, beliefs, and attitudes that lead people to pursue specific

occupations, which is the essence of participation” (Noreau and Boschén, 2010, p. S51). The current project defined participation as engagement in social roles and activities, and considered subject’s evaluation of both their abilities with respect to participation as well as satisfaction with participation.

2.2 Factors That Contribute To Participation

Participation has not been consistently characterized or operationalized in the research literature (Cardol et al., 2002; Resnik and Plow, 2009; Whiteneck and Dijkers, 2009; Woodman et al., 2014), and much remains unknown about the factors that support participation. Decisions individuals with chronic illness make regarding role participation are complex, and occur “... within the context of a disease trajectory, a health care culture, and a uniquely meaningful life” (Thorne et al., 2003, p.1349). Researchers have considered a diverse collection of functional, cognitive, mental health, and environmental variables. For this study, functional and mental health factors have been grouped together as ‘personal factors’.

Studies have shown a variety of personal factors to be associated with participation for adults with specific neurological conditions. In a prospective cohort study of adults with spinal cord injuries, van Leeuwen and colleagues (2012) found evidence that both functional status and neuroticism were related to participation outcomes. Other research has linked cognitive and executive function (Adamit et al., 2015;

Barclay-Goddard et al., 2012; Jette et al., 2005; Robison et al., 2009;) with participation outcomes in stroke populations.

Examining community dwelling adults over the age of 65 in Canada (Gilmour, 2012) and over the age of 50 in the UK (Wilkie et al., 2007), researchers found a link between physical function and participation. Similarly, functional status in older adults with chronic conditions (Anaby et al., 2009) and post stroke (Fallahpour et al., 2011; Gadidi et a., 2011; Jette et al., 2005; Mayo et al., 2014; Robison et al., 2009) has been associated with participation. However, in their cross-sectional study of older adults living with chronic conditions, Ashe and colleagues found that participation in physical activity could not be predicted by capacity to participate (Ashe et al., 2007). This is important because individuals with chronic conditions are at risk of further functional declines if they do not participate in activity to the levels they are capable of (Ashe et al., 2007).

Studies to identify the contribution of mental health factors to participation have yielded variable findings. Work with stroke patients found that mood was positively related to participation (Berges et al., 2012; Fallahpour et al., 2011; Mayo et al., 2014). Participation restriction has also been associated with lower mental health scores in adults with a variety of health conditions (Cardol et al., 2002), as well as community dwelling adults over the age of 50 (Wilkie et al., 2007). However, a study

of older adults with chronic conditions found that depression measures were not associated with participation outcomes (Anaby et al., 2009).

Similarly conflicting results have been found in examining environmental variables. Hand et al. (2014) found a positive relationship between support (both tangible support and social interactions) and participation in everyday activities, whereas Anaby et al. (2009) found no influence of social support. Both of these studies included older adults with chronic conditions, however the former study examined patient's satisfaction with participation, whereas the Anaby study used an accomplishment measure of participation. Research with stroke patients concurs with the findings of Hand et al. (2014) that support is associated with successful participation (Barclay-Goddard et al., 2012; Mayo et al., 2014; Robison et al., 2009). In other work, physical barriers (Barclay-Goddard et al., 2012; Robison et al., 2009) have been linked to decreased participation. The environmental factors considered for the current study included support, household income, marital status, and perceived stigma.

Importantly, in their study of stroke patients, Robison and colleagues found that, participants had, at 12 months, resumed only a minority of the activities that they identified as important in the initial post-stroke interview. Individuals with chronic neurological conditions are at risk of decreased participation, so identifying factors

that improve participation outcomes is a critical focus for rehabilitation efforts.

Distinguishing personal and environmental factors that support participation for individuals living with chronic neurological conditions has not been specifically undertaken. Identifying these factors may enable rehabilitation practitioners to target enablement efforts towards those skills that facilitate important participation outcomes.

More generally, studies show that those living with chronic conditions, including neurological conditions, demonstrate participation profiles that are less active, less diverse, and take place more often at home, compared with healthy peers (Adami et al., 2015; Hirschberg, 2012). Participation in home and community life are important to those with neurological conditions, however, rates of participation are lower for those with chronic conditions than their healthy peers (Fairhall, 2011). Participation has been viewed as an overall indicator of health and well-being (Piskur, 2013) and linked to successful aging (Gilmour, 2012), quality of life and life satisfaction (Stav et al., 2012). In their review of 33 articles examining participation, Stav and colleagues (2012) found that, not only does participation result in improved health outcomes, but the reverse is also true – lack of participation is related to higher mortality and decreased function. Components of participation are complex and multi-factorial and include resources, ability, and individual choice (Desrosier et al., 2005; Eriksson et al., 2013; Gignac et al., 2013; Law, 2002; Stav et

al., 2012).

Impaired role performance and less frequent participation and activity result in decreased satisfaction and quality of life ratings (Blömer et al., 2015; Dijkers, 2010; Eriksson et al., 2013). In examining contributors to participation, Anaby and colleagues defined it as daily activities and social roles (Anaby et al., 2009; Anaby et al., 2011), and found that satisfaction with participation contributed to well-being for older adults more than accomplishment ratings of participation (Anaby et al., 2011).

Participation in household and community is more of a concern to individuals than impairments or activity limitations and has significant impacts on health and well-being (Fairhall et al., 2011; Gignac et al., 2013; Gilmour, 2012; Resnick and Plow, 2009; Wilkie et al., 2007). Impaired role performance and less frequent participation and activity result in decreased satisfaction and quality of life ratings (Blömer et al., 2015; Dijkers, 2010; Eriksson et al., 2013). “... participation is the outcome that may be most valued to people with disabilities, their family members and society” (Resnick and Plow, 2009, p. 856).

2.3 Rehabilitation and Participation

The World Health Organization (WHO) recognizes participation as a key

health indicator; both an outcome and a contributor to health and well-being (Adamit et al., 2015; Anaby et al., 2009; Kessler and Egan, 2012; WHO, 2011). For health professionals who work with adults living with chronic conditions, enhancing the participation of clients is a crucial aspect of rehabilitation (Anaby et al., 2009; Chang and Coster, 2014; Dijkers, 2010; Fairhall et al., 2011; Mallinson and Hammel, 2010; Mayo et al., 2014); supporting clients to resume previously valued roles and increasing activity levels are important goals of rehabilitation (Gray et al., 2006; Levasseur et al., 2010; Mayo et al., 2014; Zhang et al., 2015). Despite the importance health professionals ascribe to participation and return to desired roles, current interventions and measures used to evaluate outcomes in rehabilitation services focus mainly on functional recovery and impairment, rather than on a return to meaningful roles and activities (Cott et al., 2007; Kessler and Egan, 2012). There has been an increasing recognition that the outcome measures used in rehabilitation need to look outside a medical model and to evaluate more than changes in impairment level (Adamit et al., 2015; Cott et al., 2007; Dijkers, 2010; Eyssen et al., 2011; Sreedharan et al., 2013).

Assessments and interventions in both clinical and research settings are generally conceptualized at the ICF levels of body function or activity, or broad measures of quality of life (Fairhall et al., 2011; Robison et al., 2009). These are reflective of an impairment reduction focus and do not assess the individual's ability to re-integrate into previous roles and activities, nor their satisfaction with participation (Adamit et

al., 2015; Bouffioulx et al., 2011). In part this may be due to the need to demonstrate treatment efficacy, such that as measures move from body structure and impairment to more conceptually broad variables such as participation, it becomes increasingly difficult to directly ascribe intervention effects to the changes observed (Salter et al., 2005).

2.4 Activation and Self-Efficacy

Engaging patients to become active participants in their care is considered essential in the delivery of quality chronic illness care and is a fundamental element of the chronic care model (Greene and Hibbard, 2012; Hibbard et al., 2004; Stanhope and Henwood, 2014). Successful implementation of such a model requires knowledgeable and activated patients who are prepared to be intensely involved in the management of their illness (Barlow et al., 2002). Some have postulated that widespread adoption of a care model that enhances and includes the resources of clients has been delayed, in part, due to a lack of consensus about what characterizes activation, how to define it, and what factors support its creation (Frosch and Elwyn, 2011; Jerant et al., 2008; Thorne et al., 2003).

Both self-efficacy and patient activation have been utilized as outcome measures and linked to successful self-management, and several researchers have described a positive relationship between self-efficacy and patient activation (Goodworth et al., 2016; Hibbard et al., 2010; Ledford et al., 2013; Van Do et al., 2015; Young et al., 2016), however the nature of these relationships have not been systematically

characterized. A proposed set of 'common data elements' to be utilized in research that furthers understanding of self-management of chronic conditions includes both self-efficacy and patient activation (Moore et al., 2016).

Self-efficacy and patient activation have both been shown to be associated with overall well-being, quality of life, and health outcomes in multiple ways, including participation in physical activity (Ashe et al., 2007; Bonsaken et al., 2012; Ellis and Motl, 2013), physical functioning (Arnold et al., 2005; Mosen et al., 2007) and increased self-management behaviours (Greene and Hibbard, 2012; Mosen et al., 2007).

2.4.1 Self-efficacy

Self-efficacy is the belief that one can execute a behavior and that it will achieve the intended outcome (Bandura, 1977). Bandura (1977) hypothesized that levels of efficacy are related to the strength of a response, effort expended, and how long a behavioural response will persist in the face of adversity. Relative to self-management behaviours for those with chronic illness, self-efficacy is believed to influence the choice of actions an individual performs to maintain health (Bourbeau, 2008). Bandura (1977) further posits that efficacy perceptions influence choice of activity and expectations of success, arguing that individuals with higher self-efficacy set higher goals for themselves, expect more successful outcomes, and persist in the face of obstacles more so than those with low perceived self-efficacy (Bandura, 2004).

Self-efficacy scales have been used as success indicators in chronic disease self-management programs for various illnesses including asthma (Mancuso et al., 2010), COPD (Bonsaken et al., 2012; Davis et al., 2006), stroke (Damush et al., 2010; Jones et al., 2009), chronic kidney disease (Curtain et al., 2008), and chronic conditions including lung and heart disease, arthritis and others (Jerant et al., 2008; Lorig et al., 2001; Lorig et al., 2010; Warsi et al., 2004). Self-efficacy has been conceptualized as an intermediary variable that supports the management of chronic illness (Arnold et al., 2005). Recent studies suggest that knowledge and self-efficacy potentiate and lead to the performance of self-management behaviours (Van Do et al., 2015; Young et al., 2016). For example, self-efficacy has been suggested as the mechanism for change in an intervention to improve health related quality of life (HRQOL) for adults with multiple sclerosis (MS) (Motl et al., 2013). Ng and colleagues (2013), also examining a population of adults with MS, found that improvements in self-efficacy and HRQOL achieved through an educational wellness program were independent of degree of disability. Participants in their study showed improvements in self-efficacy and HRQOL independent of the severity of their disability at the start of the intervention. Self-efficacy has also been suggested as the focus of an intervention for those living with spinal cord injuries (van Dieman et al., 2017; van Leeuwen et al., 2012), with one meta-analysis identifying a negative association between self-efficacy and symptoms of depression and anxiety (van Dieman et al., 2017).

Mittler and colleagues (2013) conceptualize both behavioral and cognitive components to engagement in health; where behavioral components require cognitive activation to be successful. Bandura's work on self-efficacy links personal factors and motivation to the behavioural components necessary to persist in the face of challenges (Bandura, 1977). Significantly, it is the individual's *perceived* abilities, which may or may not be different from their actual abilities, that can influence their choice of behavior (Marks et al., 2005). It is plausible that an interplay of knowledge with perceived self-efficacy and empowerment achieves effective behavioural change (Gruber, 2014; Hibbard and Greene, 2012; Jones et al., 2013; Ledford et al., 2013; Lubetkin et al., 2010). Self-efficacy has been studied, and utilized clinically, as an outcome variable, however its relationship to participation satisfaction and ability has not been explored.

2.4.2 Patient Activation

Patient activation is identified as a key element in chronic care models, and engaging patients to be active and knowledgeable participants in care is considered essential for effective self-management approaches (Hibbard et al., 2004; Stanhope and Henwood, 2014). Activation is defined as the knowledge, ability, skills and confidence to manage health (Greene and Hibbard, 2012). The concept, thus defined, was used to create a measurement tool that has been used to assess patient activation for self-management of illness, and scores on this measure have been associated with health-related outcomes (Greene and Hibbard, 2012).

Patient activation has been shown to be related to a variety of health outcomes (Greene and Hibbard, 2012; Mosen et al., 2007), and has been described by the authors of the Patient Activation Measure (PAM), as a skill building process that follows a modifiable developmental trajectory (Greene and Hibbard, 2012). Patient activation has been associated with system outcomes (e.g. fewer hospitalizations and visits to emergency departments), self-rated health, and successful adherence to self-management strategies (Chen et al., 2014; Greene and Hibbard, 2012; Lubetkin et al., 2010).

In their review of the literature, Hibbard and colleagues (2013) identified that interventions associated with higher levels of activation involve some combination of skill development, peer support, problem solving, changing the social environment, and an individualized approach. The literature is consistent in identifying self-efficacy (Ledford et al., 2013; Van Do et al., 2015), patient empowerment (Stanhope and Henwood, 2014) and education (Gruber et al., 2014; Hibbard and Greene, 2012; Hibbard and Mahoney, 2010) to be related to activation.

In summary, both activation and efficacy are considered mutable and occur along a continuum representative of the strength of a response (Bandura, 1997; Hibbard et al., 2004; Hibbard et al., 2007; Van Do et al., 2015). Both activation and efficacy are thought to be predictive of behaviour, and have been used to assess outcomes of self-management programs (Hibbard et al., 2007; Lorig and Holman, 2003; Turner et al., 2014; Van Do et al., 2015). Intuitively, clients that have the knowledge, skills and

confidence to manage their health are more likely to return to greater participation in valued life roles and activities. If client focused models of chronic care that include self-management strategies are to be widely adopted, it is imperative that the components and outcomes of this approach be consistently defined, studied and utilized in practice.

2.5 Research Questions

This research project sought to identify personal and environmental factors associated with participation in life roles for those living with chronic neurological conditions. Both satisfaction with participation and ability to participate were examined. In addition, the contributions of self-efficacy and patient activation to participation were considered.

In order to examine these relationships for people with chronic neurological conditions, the following specific questions were considered:

1. Which personal and environmental factors contribute to ability to participate?
2. Which personal and environmental factors contribute to satisfaction with participation?
3. Do self-efficacy and/or patient activation make an additional contribution to either ability to participate or satisfaction with participation?

Chapter 3 Methods

3.1 Design

Secondary, quantitative analysis of an existing data set, from the study “Living with the everyday impact of a neurological condition (LINC study)” (Versnel et al., 2013), was utilized to examine factors related to participation in life roles for those living in Canada with a chronic neurological condition. Bivariate analysis and backwards regression modeling were employed to explore and specifically identify the variables most related to participation outcomes.

The aim of the current study aligned closely with the initial objectives of the LINC study, which included exploring how the everyday lives of Canadians are impacted by living with a chronic neurological condition (Versnel et al., 2013). Further, the outcomes of interest in the original LINC study included an examination of participation in everyday activities (Versnel et al., 2013), which was also the focus of the current project. The use of secondary data analysis was, therefore, both appropriate and efficient for the current study, given the nature and rationale of the original project. The advantage of using secondary data in this work was that relevant data had already been collected (Cheng and Phillips, 2014; Coyer et al., 2005) from a large sample of Canadians living with chronic neurological conditions. It would have been unnecessarily burdensome to these individuals to ask for participation in an additional survey that would not add different information than was previously acquired. Further, these data were collected by a strong field of researchers with a depth of expertise, testing of methodology and a wide reach

(Coyer et al., 2005; Dunn et al., 2015) that would otherwise be unavailable for the breadth of the current work. Disadvantages of the secondary analysis approach include using previously fixed methodology, resulting in the need to choose from response sets collected to answer the original research questions, with no flexibility to acquire data with alternate tools (Boslaugh, 2007; Cheng and Phillips, 2014; Coyer et al., 2005). The current study somewhat mitigated this disadvantage in that the supervisory research team was comprised of members who were involved in the original data collection, thus much was known about the original rationale, methods, and design, as well as data cleaning, management and calculation of derived variables. Further, the questions addressed with the current work aligned closely with those of the original grant proposal for the LINC study.

3.2 The LINC Study

Details of the LINC study methodology are provided by Versnel and colleagues (2013); a summary follows here. The LINC data were collected as part of an initiative (the National Population Health Study of Neurological Conditions) to understand and plan for the long-term outcomes for those living with neurological conditions in Canada (PHAC, 2014). The LINC Study used a mixed-methods, nested design. The data used in the current project were collected in the first stage of the study, a cross sectional survey of adults aged 17 and over living with a chronic neurological condition. These survey results were primarily collected via online response, however to accommodate preference and ability differences, telephone as well as pencil and paper options were provided to respondents.

3.2.1 LINC Study Sample

The population of interest in the LINC study included those living in Canada with a range of chronic neurological conditions spanning neurotrauma, neuromuscular disorders, demyelinating conditions, neurodegenerative disorders, and movement disorders (Versnel et al., 2013). Several strategies were employed to recruit a convenience sample including letters of invitation and ‘tweets’ via NHCC, posters and letters of invitation via national registries of people with neurological conditions, or those who work with them, webpages and links via Facebook at universities, media presence (interviews and invited presentations), targeted recruitment of underrepresented diagnoses, and posters on community bulletin boards. Of the 1000 individuals who initiated the survey, 754 completed all sections.

3.3 Ethics

The Health Canada and Public Health Agency Research Ethics Board as well as the ethics boards of each affiliated university approved all portions of the LINC study. The province of Newfoundland and Labrador also acknowledged the study activities taking place in that province. Prior to participating, information about the study purpose, design, use of data, and all identified risks were provided to the respondents. For the purposes of the initial on-line survey, completion of the survey was considered implied consent.

As noted, the current study was consistent with the intent of the original (LINC) research proposal and therefore within the scope of work approved by Health Canada and the Public Health Agency Research Ethics Board, as well as affiliated university ethics boards. No conflicts of interest were identified for the researchers involved in the current study.

3.4 Sample

For the current study, a subsample of the LINC participants were selected. Inclusion criteria were adults 18-65 years of age living with a chronic neurological condition. Adults of traditional working age were of interest, thus the subsample included legal adults in all provinces, up to the generally utilized age of retirement (Rowland, 2012). This was to decrease the influence of lifespan changes in participation due to transition to normally expected retirement. Respondents who identified migraine as their sole neurological condition were excluded because of the episodic and time-limited (low burden) nature of their condition (Luo, 2009). In addition, because demographic variables were collected towards the end of the survey, and this information was vital to the current project, only respondents who completed all demographic sections of the survey were included.

3.5 Variables And Measurement Tools

Variables were organized according to the ICF framework. Although the definition of participation included in the ICF is vague ('involvement in a life

situation’), the model provided an appropriate organizational structure for the characterization of the variables studied. Table 1 depicts the categorization of variables and corresponding ICF domain.

Table 1: ICF Domain and Study Variables

ICF Domain	ICF Definition	Regression Grouping for Study
Participation	Involvement in a life situation	<i>Outcome Variables</i> Neuro-QoL Ability to Participate in Social Roles and Activities Neuro-QoL Ability to Participate in Social Roles and Activities
Body Function Body Structure	Physiological functions of body systems (including psychological functions) i.e. Anatomical structures (e.g. nervous system, skin, structures related to movement)	<i>Personal Factors</i> <ul style="list-style-type: none"> • HUI • Neuro-QoL Fatigue • SF-36 Mental Health Score • Comorbidities
Personal Factors Environmental Factors	Not clearly defined – includes influences particular to the individual Physical, social and attitudinal environment in which people live and conduct their lives	<ul style="list-style-type: none"> • Age • Gender • Education level <i>Environmental Factors</i> <ul style="list-style-type: none"> • Neuro-QoL Stigma • Formal and Informal Support • Income • Marital Status

Participation, as defined by the ICF (‘involvement in a life situation’), was clarified to include participation in usual life roles and responsibilities. Further, variables of

both ability to participate (hereafter abbreviated as ability) and satisfaction with participation (abbreviated as satisfaction) were delineated. For the analysis, variables reflective of the ICF domains body function, body structure, and personal factors were grouped together as *personal factors*; variables reflective of the ICF domain environmental factors were grouped as the study *environmental factors*. Personal variables were those considered to arise within the individual, whereas environmental variables were those considered to arise outside the individual to exert influence.

Based upon the literature reviewed and clinical experience, both personal and environmental variables were chosen for examination and included in regression modeling of the participation outcomes. In addition, self-efficacy and patient activation were of interest and these variables were added in the final models for each of ability and participation. Measures of self-efficacy (Bonsaken et al., 2012; Damush et al., 2010; Jerant et al., 2008; Lorig et al., 2001; Lorig et al., 2010) as well as patient activation (Greene and Hibbard, 2012; Hibbard et al., 2004; Stanhope and Henwood, 2014; Turner et al., 2014) have been widely reported in the self-management and chronic condition literature, as such these were included to determine if either or both of these contributed additional understanding to the participation variables.

3.5.1 Dependent (Outcome) Variables

3.5.1.1 Participation

Participation was conceptualized as perceptions (self-ratings) of both ability and satisfaction with participation in social roles and activities, measured using the Neuro-QoL Ability to Participate in Social Roles and Activities (short form) and Neuro-QoL Satisfaction with Social Roles and Activities (short form) scales respectively.

An identified lack of consensus related to defining and measuring dimensions of health-related quality of life led to a National Institute of Health (NIH) initiative to develop the Neuro-QoL. This was a 5 year, multi-site project funded by the National Institute on Neurological Disorders and Stroke, the intent of which was to create a brief, reliable measure that is consistent, responsive to change and applicable to a range of neurologic conditions (Cella et al., 2012; Heinemann et al., 2010).

The Neuro-QoL is a measure of an individual's perspective, their interpretation and rating of 13 quality of life domains including participation in the activities and roles that are important to them. The Neuro-QoL was developed using multiple methods including literature reviews, contributions from expert researchers, interviews and surveys with patients and focus groups. From this data, the developers identified health related quality of life items relevant to a neurological population (Gershon et al., 2012). Shortened forms were developed in an effort to reduce the

administration time while maintaining the psychometric properties demonstrated in the original version (Cella et al., 2012).

Of primary relevance to the current project, are the 2 social role domains, both used in the LINC study:

1. The Ability to Participate in Social Roles and Activities (short form) measures self-perceived ability to participate in various roles and activities over the previous 7 days. The 8-item tool uses a 5-point response scale with higher scores indicating greater perception of ability (e.g. 1 = 'never able' to perform activity to 5 = 'always able' to perform activity).
2. The Satisfaction with Social Roles and Activities (short form), similarly constructed, has different anchors for the 5-point response scale (e.g. 1 = 'not at all' satisfied to 5 = 'very much' satisfied).

The responses are summed, creating a total score for each measure, which is converted to a T-score with a mean of 50 and a standard deviation of 10.

The choice of measurement tools was influenced by consideration of the reliability, validity, sensitivity and applicability of the measure to the population of interest (Corr and Siddons, 2005). The Neuro-QoL scales were specifically designed for use in neurological populations; multiple studies have shown high reliability, internal consistency and construct validity for use in various neurological populations including Parkinson's disease (Nowinski et al., 2016), stroke (Bode et al., 2010;

Katzan et al., 2016), epilepsy (Victorson et al., 2014), AIDS (Robertson et al., 2007) and multiple sclerosis (Miller et al., 2016), as well as varied neurological populations (Cella et al., 2012; Gershon et al., 2012). Similar to other work with disease specific populations, a validation study utilizing shortened forms of both participation scales demonstrated high internal consistency with Chronbach α 's of 0.96, and correlation coefficients of $r = 0.94$ or higher, compared to the original item bank for each of the participation scales (Cella et al., 2012). In a validation study of three Neuro-QoL domains (including both participation measures used in the current study) with an adult stroke population, Bode and colleagues (2010) found good internal and external construct validity. The Neuro-QoL is a relatively new tool and validation studies are ongoing, however initial clinical validation studies have been completed, including a multi-centre project, planned from inception of the Neuro-QoL initiative, to examine reliability, validity and responsiveness in a variety of neurological populations. Reports from these studies have generally demonstrated sound psychometric properties including reliability, validity, responsiveness and strong correlations with legacy measures (Bode et al., 2010; Cella et al., 2012; Gershon et al., 2012; Miller et al., 2016; Victorson et al., 2014).

3.5.2 Influencing (Independent) Variables

3.5.2.1 Activation

Greene and Hibbard's (2012) definition of patient activation as "...having the knowledge, skills and confidence to manage one's health" (p. 520) is the only known definition of patient activation. They proposed this definition in order to develop the

only known tool for measuring patient activation - the Patient Activation Measure (PAM), a uni-dimensional interval scale (Hibbard et al., 2007). The PAM is available in two formats; the original PAM-22 with 22 items and the shorter PAM-13, with 13 items (Hibbard et al., 2004; Hibbard et al., 2005) used in the LINC study.

The PAM is a self-report tool that captures an individual's level of perceived knowledge, ability and confidence to manage their chronic condition. The PAM is a widely accepted measure that has been extensively utilized in research and tested in validation studies (Hibbard et al., 2004; Hibbard et al., 2007; Mosen et al., 2006; Packer et al., 2015; Skolasky et al., 2009; Skolasky et al., 2011). Validation studies have generally found the PAM to be psychometrically sound, providing valid and reliable results with a variety of clinical groups including chronic conditions in general (Hibbard et al., 2005; Hibbard et al., 2007; Skolasky et al., 2011) and surgical patients (Skolasky et al., 2009). For example, in a cross-sectional validation study of the PAM-13 in older adults with multiple morbidities, Skolasky et al. (2011) reported high internal consistency with a Chronbach α of 0.87. Similarly, in their examination of the PAM-13 in a group of MS subjects, Goodworth et al. (2016) found high internal consistency with a reported Chronbach α of 0.88. Positive associations with various health behaviours and outcomes have also been noted, indicative of construct validity (Skolasky et al., 2011). Similarly, in their examination of patient activation with outcomes for an adult population with varied chronic conditions, Mosen and colleagues (2007) found significant associations for the PAM-13 with both health related outcomes and process measures related to self-management

behaviours. Studying the measure for use in neurological populations, Packer and colleagues (2015) found it to have good internal consistency and construct validity, however they noted a potential for bias and measurement error at very low levels of activation and cautioned the clinical use of activation levels (categories).

The PAM scale reflects 4 stages of increasing activation, beginning with the belief in the importance of the patient role, and culminating with the patient's ability to maintain health behaviours in the face of stressful circumstances (Hibbard et al., 2005). The original PAM consisted of 22 items, however to improve feasibility, the original authors decreased the number of items, again using Rasch analysis of the original data. The authors identified items that could be eliminated while maintaining the precision and reliability of the measure (Hibbard et al., 2005). The 4-point response scale for each item ranges from 'Strongly Disagree' (=1) to 'Strongly Agree' (= 4). Numbers for each response item are summed, then a computer algorithm is applied to generate a derived score (per the Insignia Health PAM-13 manual). The derived score, used in the current study, ranges from 0 to 100 with higher scores representing greater levels of activation (Hibbard et al., 2007). The authors also provide an algorithm to convert the derived score into 4 levels of activation; however, these were not used in this study.

3.5.2.2 Self-efficacy

Consistent with the original work of Bandura (1977), and continued in the chronic disease management approaches offered by Lorig and others (Bonsaken et

al., 2014; Lorig et al., 2001; Lorig and Holman, 2003; Strecher et al., 1986; Verevkina et al., 2014), the current study defined self-efficacy as an individual's belief in their ability and persistence to perform behaviours that lead to desired outcomes.

The 6-item Self-Efficacy for Managing Chronic Disease Scale (SEMCD) was used in this study as a measure of self-efficacy.

Self-efficacy scales may be general or disease specific; both have been widely used in research over the past several decades (Lorig et al., 2001). The Chronic Disease Self-management Program was developed at Stanford University to improve self-management skills for those with chronic illness. Multiple scales were developed to assess self-efficacy for disease specific symptom management (Ritter and Lorig, 2014). To lessen the burden for patients, a six-item scale that includes factors consistent across disease groups was developed (Ritter and Lorig, 2014). The SEMCD is a six question self-rated scale to measure perceived self-efficacy or confidence to manage symptoms and health. Each item is scored on a Likert type scale from 1(not at all confident) to 10 (totally confident), thus higher numbers represent higher self-efficacy. There have been a limited number of studies to support the psychometric properties of this six item scale, however, the authors reported sound psychometric properties in validation studies, including high internal consistency (Chronbach α 0.88-0.91) with no significant floor or ceiling effects (Ritter and Lorig, 2014), in a secondary analysis of over 2800 patients with chronic conditions from six studies. Freund and colleagues (2013) examined the psychometric properties of a German version of the scale. In their convenience

sample of a population with multiple morbidities and a wide age range, they found high internal consistency (Chronbach's α 0.93), low floor effects (2.5%) and moderate ceiling effects (16-30%) per item. Further, in comparing the measure to the German General Self-efficacy Scale, they found good external validity, demonstrating a Spearman rank correlation of 0.578 (Freund et al., 2013).

3.5.2.3 Environmental and Personal Influencing (Independent) Variables

Variables were considered for inclusion in this work, based on a review of relevant literature and guided by clinical rationale. Based on the ICF-based working model, variables were divided into 2 groups: environmental and personal. These groups were entered into the regression analysis as blocks (see methodology).

Environmental variables were grouped as the factors included in the ICF domain 'Environmental Factors'. These include factors of the physical, social and attitudinal environments of individuals (WHO, 2013). The following were available from the LINC study dataset:

1. Social support. Previous work has identified that availability of support, as well as social influence, may impact accessibility and likelihood of participation (Barclay-Goddard, et al., 2012; Hammel et al., 2006, Law, 2002). In her review of the existing literature relative to support in chronic illness self-management, Gallant (2003) found a modest positive relationship between social support and self-management behaviours (2003). In the current study, support was defined as informal assistance (from family or

friends) or formal support (support services) received, because of the respondent's neurological condition, to accomplish a task or activity. This variable was derived using data from two modules of the Canadian Community Health Survey (also collected in the Survey on Living with Neurological Conditions in Canada (SLNCC)), one module measuring use of formal (paid) care and one measuring use of informal care provided by family and friends at home, work or school over the previous 12 months. Data from the two modules was combined to create a derived variable with three categories: 1) formal care only, 2) informal care only or 3) both formal and informal care received.

2. Marital status. Higher levels of support have been associated with better self-management outcomes (Gallant, 2003) and, conceivably, marital status impacts both availability of support and income to financially support participation. Marital status was categorized as 1) married or common law, 2) single, or 3) widowed, divorced or separated.
3. Income level. Income level has been shown to be related to health (Cott et al., 1999; Gilmour, 2012; Wilkie et al., 2007). This was measured as reported annual household income less than \$20 000, or \$20 000-59 999, or \$60 000-89 999, or over \$90 000.
4. Perceived Stigma. Stigma was conceptualized as feelings of negativity or disapproval that an individual believes to be projected upon them. Neuro-QoL Perceived Stigma scores were used as a measure of stigma, with lower scores on this scale indicating lower perceived stigma. Higher levels of

perceived stigma result in decreased opportunities for participation (WHO, 2006).

5. Education level. Education has been associated with greater levels of activation (Goodworth et al., 2016; Van Do et al., 2015). This was collapsed to categories of: less than secondary, secondary graduate, some post-secondary, post-secondary graduate.

Personal variables were those included in the ICF domains 'Body Function' and 'Body Structure', representing the physiological and anatomical functioning of individuals. In addition, because 'personal factors' are not well clarified in the ICF, additional factors identified as particular to the individual were grouped for analysis, along with body function and structure, as the 'personal' block of variables. Together these included:

1. Impairment. Individuals with greater impairment are likely to experience greater barriers to participation (Fallahpour et al., 2011; Gadidi et al., 2011). The Health Utilities Index (HUI), used in the current study, provides a basis for describing health status. It has been used in clinical, health economics, and population studies as a means to standardize the assessment of health status and health related quality of life (Horsman et al., 2003; Mo et al., 2004). It has been shown to be a comprehensive, reliable, responsive and valid measure of health status (Horsman et al., 2003; Luo et al., 2009). The HUI has been used to describe individual health states, long term outcomes, and treatment effectiveness, as well as the health status of populations (Horsman

et al., 2003). The HUI is intended to classify health states as a functional capacity, thus the score represents the extent to which deficits are perceived, by the community at large, to interfere with functioning rather than the level of performance (Feeny et al., 2002).

This well accepted measure has been used in hundreds of studies applied to various populations (Horsman et al., 2003). The HUI is a preference based tool that describes an individual's overall functional level, as perceived by the community, based on 8 attributes including: vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain. The scores on these 8 attributes are used to derive a summary value, based on the importance the general public ascribes to each attribute, where most preferred health = 1 and death = 0.00. Negative scores are possible and represent a rating worse than death. As a preference based tool, the HUI definition of health focuses on impairments and defines health in terms of capacity, not psychosocial or role functioning (Abel et al., 2017).

2. Presence of Non-neurological Comorbidities. The presence of comorbidities may increase overall levels of impairment and influence participation (Barclay-Goddard et al., 2012; Desrosiers et al., 2005; Wilkie et al., 2007). Non-neurological comorbidities considered in the LINC study were heart disease, diabetes and depression. These were collapsed into a dichotomous variable indicating either presence or absence of comorbidities.

3. **Fatigue.** Fatigue was included as an influencing variable because it is a common symptom of neurological conditions and is known to impact participation (Asano et al., 2015; Boosmam et al., 2011; Ingles et al., 1999; Maaijwee et al., 2014). This study utilized the Neuro-QoL Fatigue Scale. Lower scores on this scale are indicative of less impairment/greater function. See previous section for a description of the development and psychometric properties of the Neuro-QoL scales.
4. **Mental Health.** Depression and anxiety are commonly associated with neurological conditions and have been shown to impact on participation (Anaby et al., 2009; Cardol et al., 2002; Fallapour et al., 2011; Skolarus et al., 2014). Three measures were considered: The Neuro-QoL Depression Scale, the Neuro-QoL Anxiety Scale, and the Medical Outcomes Scale, short form (SF-36). A description of the Neuro-QoL, including the development of the measure and psychometric properties, is provided above. The SF-36 was designed to assess health-related quality of life. The measure has been widely studied and generally demonstrates high internal consistency, with the exception of the 2 item social functioning subscale (Rutta et al., 1994). Adequate construct validity has been shown in various populations including older adults (Walters et al., 2001), stroke (Hagen et al., 2003) and surgical patients (Bunevicius, 2017). It has become a widely reported measure of health status used in health policy as well as clinical and research outcomes to assess health related quality of life (de Haan, 2002). It was originally developed in 1992 as part of a medical outcomes study and adapted to its

current form. Two sets of summary scores may be derived from the licensed version of the SF-36, one measuring physical health (the Physical Composite Score – PCS) and one measuring mental health (the Mental Composite Score – MCS). Only the Mental Health Composite Score, derived from the scaled scores on the Social Functioning, General Mental Health, Emotional Problems, and Vitality domains, was utilized in the current study. Norm-based scores, with a mean of 50 and standard deviation of 10 were calculated using SF-36 provided software.

5. Age in years was stratified by age decade for the sample cohort.
6. Gender, reported as male or female, was included as it is a generally described demographic variable.

3.6 Data Retrieval, Cleaning And Analysis

Data for the variables of interest were transferred from the main LINC data set. Data for respondents who met the age criteria and completed the demographic section of the survey were included. All variables were assessed for missing data points prior to analysis. Exclusion criteria were applied and the data for presence of co-morbidities was collapsed into a dichotomous yes/no response set. The personal and environmental variables to be considered were identified.

Summary statistics were first calculated for all variables. This was followed by bivariate analysis examining the association between each of the independent and dependent variables (ability to participate and satisfaction with participation).

Continuous variables were examined using Pearson correlations; ANOVAs assessed relationships between categorical variables. Correlation coefficients were assessed as follows: r values 0-0.19 were considered very weak, 0.20-0.39 were considered weak, 0.40-0.59 were moderate, 0.60-0.79 were strong and those 0.80-1.0 considered very strongly correlated (Evans, 1996). Linear regression analysis, with backwards removal of non-significant variables, was then used to examine the relationships of the influencing variables with the outcome (participation) variables.

Variables that demonstrated at least moderate associations ($r \geq 0.40$) with the dependent variables of interest (satisfaction or ability) and limited collinearity were retained and used in the linear regression modeling. In order to specify the influence of *environmental* factors and *personal* factors, these variables were added as groups. Backwards elimination of non-significant variables was utilized to identify those variables in each group that most contributed to each participation outcome variable. Because patient activation and self-efficacy were primary variables of interest, one of these variables was included in a model for each of the dependent variables. A parallel process was followed for each of:

1. Ability to participate, self-efficacy
2. Ability to participate, patient activation
3. Satisfaction with participation, self-efficacy
4. Satisfaction with participation, patient activation

This resulted in four models for each outcome variable (Table 2 below).

Table 2: Linear Regression Models

Variable	Ability Model	Satisfaction Model
Personal Block (+)	1a	2a
Environmental Block (+)	1b	2b
Self-Efficacy (Or)	1c	2c
Activation	1d	2d

Personal variables and environmental variables that met the threshold for inclusion (moderate correlation with the dependent variables) were identified and input as blocks to the models. The personal variables were the first block added to the model. The variable with the least significance over 0.10 was excluded from subsequent analysis and the model was run again until all variables were significant ($p \leq 0.05$). The block of retained environmental variables was then added and the process repeated until all variables in the model demonstrated significance at a level $p \leq 0.05$. Finally, to determine if measures of self-efficacy or patient activation added additional explanation to the models, SEMCD or PAM scores were added and again, variables that did not meet the threshold ($p \leq 0.05$) were removed until all variables in the final model demonstrated significance. This algorithm was repeated for each of the outcome variables of ability and satisfaction. Backwards removal was used in the regression modeling in order to determine the specific personal and environmental variables most related to participation outcomes. Keeping the variables grouped was the most effective way to determine whether environmental variables and/or personal variables were useful in explaining participation outcomes.

Chapter 4 Results

4.1 Sample Characteristics

A total of 614 people met the criteria for inclusion. Respondents were predominantly (67%) female, and highly educated (72% post-secondary graduates) (Table 3). The majority were married or in common law relationships (59%) and 78% were between the ages of 36 and 65, traditionally considered prime productive, wage earning years. Only 70% of respondents reported household income and of these 35% reported annual household income between \$20 000 and \$59 999. Only 25% reported an annual household income of \$90 000 or greater (Table 3). Comparatively, approximately 46% of Canadian households with couples families reported income over \$90 000 in 2013 (Stats Canada, 2013).

Table 3: Summary Statistics for Categorical Personal and Environmental Influencing Variables

Personal and Environmental Variables	Frequency	Percent
Personal Variables		
Gender (n=613)		
Male	200	33
Female	413	67
Education Level (n=593)		
Less than Secondary	37	6
Secondary Graduate	77	13
Some Post-secondary	52	9
Post-secondary Graduate	427	72
Marital Status (n=614)		
Married or Common-law	365	59
Single/Never Married	156	25
Widowed/Separated/Divorced	93	15
Age (n=614) (mean = 47) Years		
<=25	35	6
26-35	99	16
36-45	108	18
46-55	192	31
56-65	180	29
Non-Neuro Comorbidity*		
No	328	53
Yes	288	47
Environmental Variables		
Income (n=434)		
<\$20 000	86	20
\$20 000-\$59 999	153	35
\$60 000-\$89 999	86	20
\$90 000 or more	109	25
Assistance		
No Support	299	49
Assistance from Support Service only	31	5
Assistance from family/friends only	161	27
Assistance from family/friends & service	116	19

*Presence of heart disease, diabetes or depression

Forty-nine percent of participants reported no informal or paid support and 27% reported receiving only unpaid/informal support. Conditions most commonly reported were MS (27%), migraine (22%), brain injury (17%), and epilepsy (16%). For a complete list of conditions refer to Appendix A.

Table 4: Summary Statistics for Continuous Dependent and Influencing Variables

Dependent and Influencing Variables	Observations (number)	Mean	Standard Deviation	Range Min	Range Max
<i>Dependent Variables</i>					
Neuro-QoL Participation (Satisfaction)	610	43.74	5.58	28.4	60.5
Neuro-QoL Participation (Ability)	610	45.24	7.63	24.1	60.2
<i>Influencing Variables</i>					
SEMCD	612	6.04	2.24	1	10
PAM	609	62.2	15.95	27.1	100
<i>Personal Variables</i>					
HUI	577	0.46	0.31	-0.28	1
Neuro-QoL Fatigue	614	51.74	8.77	29.5	74.1
SF-36MH Norm-based Score	613	44.66	11.4	14.24	63.95
<i>Environmental Variables</i>					
Neuro-QoL Stigma	613	52.95	7.98	39.2	81.5

SEMCD= Self-Efficacy for Managing Chronic Disease Scale,
PAM=Patient Activation Measure, HUI =Health Utilities Index,
MH=Mental health

Continuous variables demonstrated roughly normal distribution patterns, with the exception of specific Neuro-QoL variables. The distributions for the Neuro-QoL variables were notable for their floor/ceiling effects (Figures 1, 2 and 3), with greater frequency of responses at the low end of the variable where low scores are indicative of less impairment (stigma) and at the high end of variables where high scores indicate greater function (participation variables). The sample demonstrated a range of impairment (-0.28-1.00) with a mean of 0.46 on the HUI (Table 4), which may be considered indicative of severe disability (Feng et al., 2009).

Figure 1: Neuro-QoL Ability to Participate Distribution

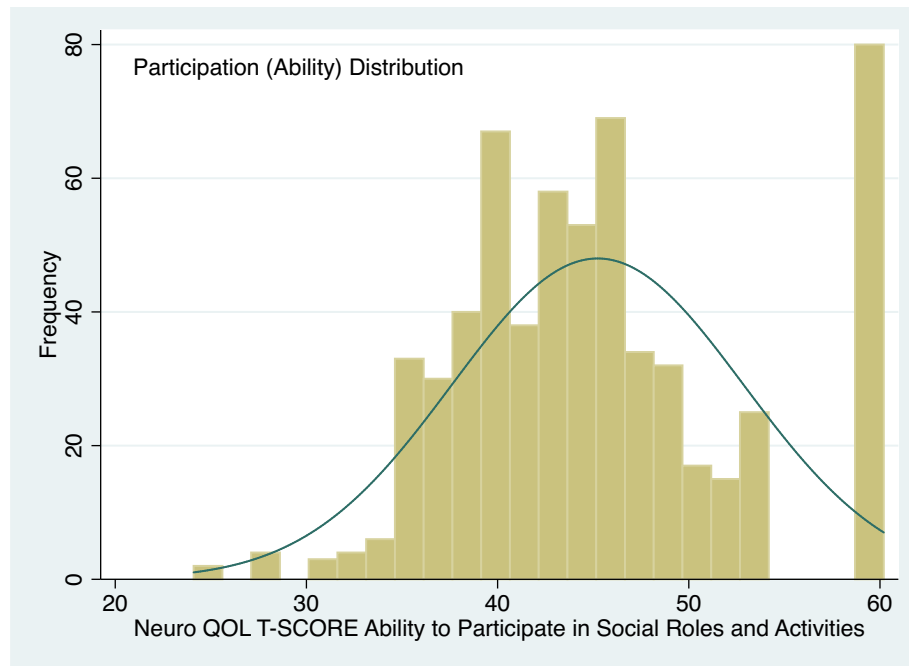


Figure 2: Neuro-QoL Satisfaction with Participation Distribution

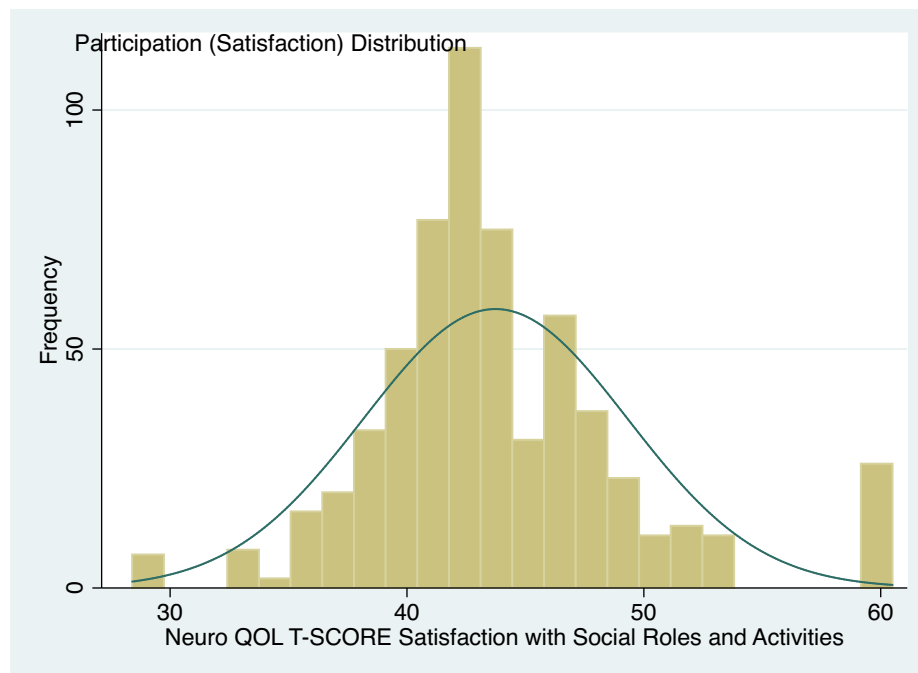
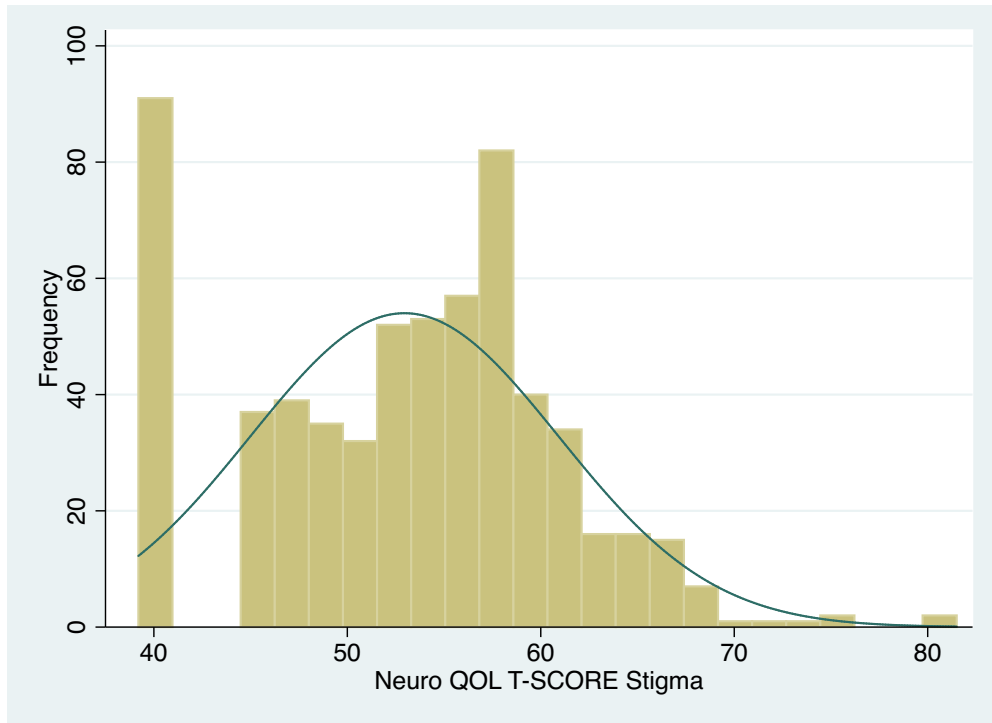


Figure 3: Neuro-QoL Stigma Distribution



4.2 Bivariate Analysis

In this study, the two dependent variables (participation ability and satisfaction) were strongly correlated ($r=0.69$), suggesting the two are related but different constructs.

Both patient activation and self-efficacy demonstrated moderate positive correlations with the Neuro-QoL measures of participation (Table 5). Self-efficacy scores showed a stronger relationship for both ability to participate ($r=0.56$) and satisfaction with participation ($r=0.54$) than did PAM scores ($r=0.44$ and 0.41 , respectively). The two measures demonstrated a moderate level of correlation ($r=0.56$) with each other.

4.2.1 Bivariate Analysis – Personal Factors

The personal factors represented both physical (HUI, fatigue, presence of non-neuro comorbidities) and mental health (SF-36 norm based mental health component score, depression, anxiety) variables (Table 5). Examining the relationships between personal variables and the two participation variables, the Health Utilities Index (HUI), held moderate positive correlations for both the Neuro-QoL measures of ability to participate ($r=0.55$) and satisfaction with participation ($r=0.49$). Fatigue was moderately negatively correlated with both measures of participation as well as self-efficacy and showed a weak negative correlation with PAM (Table 5). Depression showed moderate negative correlations with the measures of participation (ability and satisfaction) and was moderately associated

with fatigue ($r=0.55$) and stigma ($r=0.51$) variables, and was very strongly (negatively) associated with the overall mental health variable from the SF-36 ($r=-0.80$). Fatigue was strongly associated with the participation ability variable ($r=-0.65$) and moderately negatively correlated with the participation satisfaction variable ($r=-0.55$). Following the bi-variate analyses, the Neuro-QoL variables Depression and Anxiety were excluded from the regression modeling. The Neuro-QoL Anxiety variable was only weakly correlated with satisfaction. Given the very strong negative correlation of the Neuro-QoL Depression variable with the SF-36 norm-based mental health score, and similar correlations with the dependent variables, it was decided to utilize a tool other than the Neuro-QoL to represent the mental health component of personal factors. The SF-36 norm-based mental health composite score was chosen, as it is comprised of a number of mental health factors, and is a widely reported measure.

Table 5: Bivariate Analysis (Pearson Correlations), Continuous Variables*

Variable	Neuro-QoL Ability P	Neuro-QoL SatisfactionP	SEMCD	PAM	HUI	Neuro-QoL Fatigue	Neuro-QoL Depression	Neuro-QoL Anxiety	Mental health (SF36)	Neuro-QoL Stigma
Dependent Variables										
Neuro-QoL Ability P	1									
Neuro-QoL SatisfactionP	0.69	1								
Influencing Variables										
SEMCD	0.56	0.54	1							
PAM	0.44	0.41	0.56	1						
Personal Variables										
HUI	0.55	0.49	0.43	0.33	1					
Neuro-QoL Fatigue	-0.65	-0.55	-0.57	-0.33	-0.49	1				
Neuro-QoL Depression	-0.49	-0.48	-0.56	-0.44	-0.38	0.55	1			
Neuro-QoL Anxiety	-0.45	-0.39	-0.46	-0.39	-0.33	0.49	0.75	1		
SF-36 MH Norm-based Score	0.44	0.42	0.54	0.39	0.33	-0.51	-0.8	-0.7	1	
Environmental Variables										
Neuro-QoL Stigma	-0.56	-0.53	-0.47	-0.34	-0.41	0.44	0.51	0.47	-0.41	1

* All statistically significant ($p < 0.05$)

SEMCD= Self-Efficacy for Managing Chronic Disease Scale,
PAM=Patient Activation Measure, HUI =Health Utilities Index,
MH=Mental health

Table 6: Bivariate Analysis, Categorical Variables*

Categorical Variables	Participation (Ability)	Participation (Satisfaction)
Personal Variables <i>ANOVA</i>		
Comorbidity	Sig diff	Sig diff
<i>Paired t-test</i>		
Gender	No sig diff	No sig diff
Environmental Variables <i>ANOVA</i>		
Support	Sig diff all groups vs. no support	Sig diff all groups vs. no support
Marital Status	Sig diff widow/separ/div & both other groups	No sig diff
Income	sig diff lowest to highest 2 groups and second lowest to highest	sig diff highest to lowest groups only

*All statistically significant $p \leq 0.05$

Statistically significant differences were found between both Neuro-QoL ability to participate and Neuro-QoL satisfaction with participation and comorbidity (Table 6). Paired t-test analyses found no differences between either participation variable and gender (Table 6). Both categorical personal variables (comorbidity and gender) were retained for consideration in the regression modeling. Gender could have been excluded, however to be conservative, and because it is a widely reported variable, the decision was made to retain it in the regression analysis.

4.2.2 Bivariate Analysis – Environmental Factors

Environmental factors examined included social support (marital status and formal/informal support), household income, and perceived stigma. Using oneway

analysis of variance (Table 6), statistically significant differences were found between Neuro-QoL ability to participate and marital status, support and income ($p \leq 0.05$). Similarly, significant differences were found between Neuro-QoL satisfaction with participation and type of assistance, as well as income level. Based on these results, marital status, support and income were all kept for further analysis in the regression modeling.

Moderate negative correlations (Table 5) were found for ability to participate and stigma ($r = -0.56$) and satisfaction with participation and stigma ($r = -0.53$). Thus stigma was kept for further analysis.

In summary, the variables included in the regression modeling were those that met the threshold of moderate correlations ($r \geq 0.40$) with both dependent variables.

Based on the bivariate analyses, the regression models included:

- Personal factors - HUI, fatigue, mental health, comorbidity.
- Environmental factors - support, marital status, income, perceived stigma.

4.3 Regression Analysis

Because of the floor/ceiling effects noted in the Neuro-QoL distributions, both truncated and Tobit (censored) regression analyses were run, then compared with the linear regression results. Tobit regression is used when the data suggests there are limits on the measurement scale of the outcome variable, such that the true value might be equal to, or be higher (or lower) than indicated. Truncated

regression predicts an outcome variable from a truncated sample of its distribution. Censored regression thus suggests limits of the measurement, where truncated regression suggests limits of the outcome variable for the sample. The results from all three analyses were similar; showing the same trends, same order of non-significant variables excluded, same final variables for each model, and very similar final coefficients. Therefore, because linear regression is more commonly reported in the literature and easier to interpret, only results of the linear regression analysis are reported.

For the backward linear regression modeling, four parallel analyses were run to examine self-efficacy relative to each dependent variable, and patient activation relative to each dependent variable (Table 2). Variables were input as blocks with personal variables (*HUI, fatigue, mental health, comorbidities, age, gender, and education level*) included in the first block. The variable with the least significance over 0.10 was eliminated and the analysis re-run until all retained variables (*HUI, fatigue, and mental health*) demonstrated significance (final $p \leq 0.05$). Next the block of environmental variables was added (*stigma, support, marital status, and income level*) and the process repeated. The environmental variables retained as significant were *stigma* for both participation outcomes, and *support* for ability only. Self-efficacy or activation variables were added last. This algorithm was repeated for all models (Table 7). Note that the threshold for retention was, to be conservative, $p \leq 0.10$, however once variables that were over the threshold were removed, all remaining variables (final models) were significant at $p \leq 0.05$.

Table 7: Results of Regression Analysis with Personal and Environmental Variables Added as Blocks

Variable Block	Neuro-QoL Ability Participation		Neuro-QoL Satisfaction Participation	
1. Personal	Adjusted R ² = .50 Model 1a n=568		Adjusted R ² = .38 Model 2a n=568	
	β (se)	95 % CI	β (se)	95 % CI
HUI	7.11 (.84)	5.46-8.77	4.79 (.69)	3.42-6.15
NQ Fatigue	(-).38 (.03)	(-).44-(-).31	(-).21 (.03)	(-).26-(-).16
MH	.09 (.02)	.04-.14	.09 (.02)	.05-.12
2. Environmental	Adjusted R ² = .56 n=558 Model 1b		Adjusted R ² = .43 n= 566 Model 2b	
	β (se)	95 % CI	β (se)	95 % CI
HUI	4.56 (.88)	2.88-6.36	3.64 (.69)	2.29-4.99
NQ Fatigue	(-).33 (.03)	(-).38-(-).26	(-).18 (.03)	(-).23-(-).13
MH	.06 (.02)	.02-.11	.05 (.02)	.01-.09
NQ Stigma	(-).23 (.03)	(-).30-(-).17	(-).20 (.03)	(-).25-(-).14
Support				
• Formal	(-).2.03 (1.04)*	(-).4.08-.02	NS	NS
• Informal	(-).2.20 (.53)	(-).3.24-(-).1.16		
• Both	(-).2.49 (.63)	(-).3.73-(-).1.25		
3.1 SE	Adjusted R ² = .58 Model 1c n = 559		Adjusted R ² = .46 Model 2c n= 566	
	β (se)	95 % CI	β (se)	95 % CI
HUI	4.15 (.88)	2.42-5.88	3.26 (.68)	1.92-4.60
NQ Fatigue	(-).30 (.03)	(-).36-(-).23	(-).15 (.03)	(-).20-(-).10
NQ Stigma	-.21 (.03)	(-).27-(-).15	(-).18 (.03)	(-).23-(-).13
Support				
• Formal	(-).2.09 (1.01)	(-).4.09-(-).09	NS	NS
• Informal	(-).2.02 (.52)	(-).3.05-(-).99		
• Both	(-).2.29 (.62)	(-).3.5-(-).1.08		
SEMCD	.61 (.12)	.37-.85	.53 (.10)	.33-.73
3.2 Activation	Adjusted R ² = .57 Model 1d n=555		Adjusted R ² = .45 Model 2d n=563	
	β (se)	95 % CI	β (se)	95 % CI
HUI	3.98 (.89)	2.24-5.71	3.25 (.69)	1.89-4.60
NQ Fatigue	(-).33 (.03)	(-).39-(-).27	(-).19 (.02)	(-).24-(-).14
NQ Stigma	(-).22 (.03)	(-).28-(-).16	(-).18 (.03)	(-).23-(-).13
Support				
• Formal	(-).2.43 (1.02)	(-).4.44-(-).43	NS	NS
• Informal	(-).2.01 (.52)	(-).3.03-(-).98		
• Both	(-).2.21 (.62)	(-).3.42-(-).99		
PAM	.08 (.01)	.05-.11	.06 (.01)	.04-.09

* p < = .052, all other values p < = .05

HUI = Health Utilities Index	MH= SF-36 Mental health, norm-based score	SE = Self -Efficacy
SEMCD= Self -Efficacy for Managing Chronic Disease Scale	PAM = Patient Activation Measure	
n = Number of observations	β = coefficient	
se = standard error	CI = confidence interval	NS = Not significant for model

Question 1: Which personal and environmental factors contribute to ability to participate?

For both final ability models (1c and 1d) the personal factors that remained significant were impairment and fatigue, and the environmental factors that remained significant were support and stigma. The regression coefficients for HUI (impairment) and support were the highest.

Comparing the ability to participate models (Table 7) for self-efficacy and activation, the adjusted R² ranged from 0.50 to 0.58, with the final models explaining 58% (SEMCD – model 1c) and 57% (PAM – model 1d) of the variance. Although HUI remained a significant variable throughout the modeling, the strength of the coefficient dropped when the environmental variables were added (7.1 to 4.6), and further decreased when SEMCD (4.1) or PAM (3.9) were added to the model. Despite this, HUI was consistently the highest regression coefficient in the models. The mental health variable (SF-36 norm-based score) remained significant in the models until the SEMCD or PAM variable was added, after which it fell below the threshold for inclusion in the models.

Question 2: Which personal and environmental factors contribute to satisfaction with participation?

For both final satisfaction models (2c and 2d) the personal factors that remained significant were HUI and Fatigue; the only environmental variable that remained

was Stigma. Thus, in contrast to the ability to participate model, support was not significant. Comparing satisfaction participation models, the adjusted R^2 ranged from 0.37 to 0.46, with the final model accounting for 46% (SEMCD – model 2c) and 45% (PAM – model 2d) of the variance. As with the ability models, the HUI regression coefficients were the highest, although they were not as high as the coefficients in the ability to participate models. As in the ability models, the HUI coefficients dropped once the environmental variables were added (4.8 to 3.6), and again decreased with the addition of SEMCD (3.2) or PAM (3.2). Similar to the ability to participate models, the mental health variable became non-significant with the addition of SEMCD or PAM. The strongest coefficient values were again HUI, and the coefficients for all significant variables (HUI, Fatigue, Stigma, and self-efficacy or PAM) were lower than those in the ability to participate models.

4.3.1 Regression Summary

The regression coefficients are a measure of how much change is expected in the dependent variable given a one-unit change in the independent variable, keeping all other variables constant. Examining the coefficients from the final regression models, the HUI demonstrated the largest regression coefficient values for all eight models, ranging from 3.25 (CI=1.89-4.60) to 4.15 (CI=2.42-5.88). The HUI summary score provides an overall functional level based on 8 attributes, where most preferred health = 1 and death = 0.00 (negative scores represent a rating worse than death). The recommended minimally important difference on the HUI is 0.03 (Luo et al., 2009). The coefficient for HUI was greater for ability to participate than for

satisfaction with participation, suggesting that it may not have the same relationship with an individual's ability to participate as with satisfaction with participation. However, as noted above, there was significant overlap of confidence intervals between the ability and satisfaction models for all of the significant variables, with the exception of fatigue (for which there was no overlap).

Comparing the two final models for ability and satisfaction, after controlling for personal and environmental variables and including either self-efficacy or patient activation, there was a relatively greater proportion of the variance explained for the ability to participate versus satisfaction with participation ($r = 0.57-0.58$ versus $0.45-0.46$) model. Use of formal and informal support remained significant in the models examining ability to participate, but was not significant in the satisfaction with participation models. All four models included HUI, Fatigue and Stigma. Although the coefficients for the variables were stronger in the ability models (1a, b, c, and d) than in the satisfaction models (2a, b, c, and d), confidence intervals for all coefficients demonstrate significant overlap between the two models.

Question 3: Do self-efficacy and/or patient activation make an additional contribution to either ability to participate or satisfaction with participation?

The contribution of self-efficacy or patient activation was similar in all models regardless of outcome (ability or satisfaction). After the addition of the personal and environmental blocks, self-efficacy and patient activation explained an additional 1-

2 % of the model variance. For both ability to participate and satisfaction with participation, final adjusted R^2 were similar regardless of which variable was added. Statistically significant personal and environmental variables were similar (with the exclusion of support in the satisfaction with participation models), with similar coefficient values in the final models. Thus, the final regression models were able to account for similar levels of variation whether the PAM or SEMCD were used. Further, the variables that were significant in the final models were identical for PAM and SEMCD for each of the ability and satisfaction dependent variables. However, SEMCD and PAM were significant in the final models and added to the accuracy of the models. Adjusted R^2 increased from 0.56 to 0.58 for SEMCD and 0.57 for PAM in the ability model and from 0.43 to 0.46 (self-efficacy) and 0.45 (PAM) for the satisfaction models. Although these added only a small percentage (1-2%) to the accuracy of the models, the addition of either variable decreased the coefficients of the HUI, indicating that targeting activation or self-efficacy may to some degree moderate the effect of impairment on participation outcomes.

In both the ability and satisfaction models, the final model regression coefficients had higher values for self-efficacy than activation. For example, the effect of a one unit change on the self-efficacy scale had a greater impact on ability to participate versus the PAM (0.61(CI=.37-.85) vs. 0.08 (CI=.05-.11)), however the PAM scale ranged from 0-100, whereas SEMCD is a 10 point scale.

Chapter 5 Discussion

This research project sought to identify personal and environmental factors that facilitate participation in life roles for those living with chronic neurological conditions. Further, the contribution of self-efficacy and patient activation to participation were examined.

This study confirms previous work that has shown participation ability and satisfaction are not equivalent (Anaby et al., 2011; Gignac et al., 2013), and demonstrates that not all the same factors are associated with both satisfaction and ability. Using multiple regression analysis, the final models explained approximately 12% more of the variation in ability than satisfaction. The personal variables of HUI and Fatigue, and the environmental variable Stigma were significant in all four final models. Support was also a significant variable in the ability models but not the satisfaction models. The addition of the chosen environmental variables accounted for approximately an additional 5% of the variation in the models from the personal variable contribution, however the coefficients for the environmental variable 'Support' were among the highest in the ability models. Regression coefficients are a measure of how much change is expected in the dependent variable given a one-unit change in the independent variable, assuming all other influencing variables are held constant.

An unexpected finding was that the mental health variable (SF-36 norm-based mental health score) was not significant in any of the final models. This variable did

remain in the models until the final self-efficacy or patient activation variables were added, at which point it dropped below the threshold for inclusion. Depression and anxiety are commonly linked with neurological conditions and have been shown to be associated with participation outcomes (Cardol et al., 2002; Fallapour et al., 2011). In the bivariate analysis, the mental health variable was only weakly correlated with PAM and moderately correlated with SEMCD. In the current study, the Neuro-QoL scales for anxiety and depression were excluded from the regression modeling, in favour of an overall mental health variable; future research could include these, or examine other specific measures of depression and anxiety rather than a composite or overall measure of mental health.

The results of the current study offer several findings of importance to clinicians working with this population; these are discussed below.

5.1 Ability To Participate And Satisfaction With Participation Are Related But They Are Not Explained By The Same Variables

A significant finding in our study was that, overall, both the environmental and personal variables included held stronger relationships, and accounted for more of the variability in participation relative to ability than to satisfaction. In addition, support was a significant variable for the ability but not the satisfaction with participation models.

5.1.1 Support

Although both personal and environmental variables are important for participation, the contributing variables were not identical as support contributed to ability but not satisfaction with participation. The coefficients for the support variables were among the largest in the models indicating that, if this can be influenced, it might be a target for interventions to improve participation outcomes. These results are consistent with previous work that identifies support as an important factor in participation. In their review of the stroke literature related to interventions that included support of friends and family, Bakas and colleagues (2014) found some evidence of positive relationships between improved physical function, social function, and quality of life for interventions that included support for survivors. Also examining a stroke population, Barclay-Goddard et al. (2012) found that social support was associated with participation.

Alongside the formal healthcare system, individuals with chronic disease, including those with neurological conditions, are often reliant on informal supports for household and community participation. “The experience of managing chronic illness does not occur in isolation but requires a complex interaction of resources if successful adjustment is to occur and be maintained” (White et al., p222). Many care partners provide instrumental and emotional support for participation (Morris et al., 2014). As the current study suggests, support may work directly to enhance participation ability. Additionally, in a review article, Gallant (2003) found evidence

that greater levels of social support were related to better self-management behaviours for those with chronic conditions; thus a secondary route of influence may be through the strengthening of self-management behaviours that lead to improved participation outcomes.

Interestingly, in one cross-sectional survey of older adults with chronic conditions, researchers found that those who received tangible support had higher satisfaction with participation (Hand et al., 2014). This contrasts with the findings of our study, where support was associated with ability to participate, but not satisfaction with participation. The researchers in the former study examined an older adult (over 60) population with a variety of chronic conditions and they were specifically examining satisfaction with participation. Our study included participants with a maximum age of 65 and it may be that outcomes for younger and/or neurological populations are different. Some neurological conditions impact individuals at a younger age (WHO, 2006) and it may be that changes to participation patterns create greater dissatisfaction in this group. Further, neurological conditions, such as MS, can be unpredictable and/or are progressive in nature and this might lead to greater dissatisfaction. Support is a mechanism to enable participation, however its presence does not translate directly to improved participation (Mayo et al., 2014), and although the opportunity to access support may be important in removing barriers to participation, this may not lead to greater satisfaction.

The results indicate that the same variables are not explanatory for both satisfaction and ability. Although most of the variables that were significant in the final models were the same, the coefficients were stronger and the variables were together more explanatory for the ability than satisfaction models. Choice of activity and the meaning that one derives from participation are highly personal (Hammel et al., 2008). As such, it may be that the factors that contribute to satisfaction are more individualized and more difficult to uncover; further it may be that the variables utilized in this study were not the components most related to satisfaction.

Qualitative investigation of individual experiences might expose additional factors that could be considered. Whatever the path, future work should examine additional variables to identify those with stronger relationships to satisfaction with participation.

5.1.2. Impairment

The HUI was used in this analysis as a measure of impairment, with higher scores indicating a state closer to 'normal'. It was not a surprising finding that HUI scores were significant in each of the final models, as greater levels of impairment can create challenges to the ability to participate. Coefficients for HUI were higher for the ability participation models; less impairment would result in less difficulty with the ability to participate, however this does not necessarily translate into satisfaction. Further, the coefficients were highest prior to the addition of the environmental variables, suggesting that environmental factors might have a mediating effect that offsets some of the barriers imposed by impairments that

impede participation. The HUI demonstrated the largest coefficient values in all four final regression models, indicating that if impairments can be improved, these are a potential target for intervention.

Current interventions and measures used to evaluate outcomes in neuro-rehabilitation services focus mainly on functional recovery and impairment, rather than on a return to meaningful roles and activities (Anaby et al., 2011; Cott et al., 2007). The findings of this study partially support this historical focus on reducing impairment, as reducing impairment may help support participation overall. The coefficients for HUI were the strongest in all models, and associated with both satisfaction and ability. However, a sole focus on reducing impairment may be an unrealistic long-term strategy for improving participation in life roles. Neurological conditions may be progressive, or symptoms may be intermittent (e.g. MS), and even for those that are not progressive, there are limits to the amount of impairment reduction that is possible (e.g. spinal cord injury, brain injury).

5.2 Rehabilitation clinicians should include interventions to address stigmatization to improve participation outcomes

Stigma has not typically been the focus of rehabilitation programs, nor has it been well researched for those with neurological conditions. However, in the current study, stigma was significant in both the ability and satisfaction models. This concurs with the recent work of Warner and colleagues (2018) who identified that

stigma is an important factor in social participation (Warner et al., 2018).

Stigma may be conceptualized as a relationship between the differentness of an individual and societal negative valuations about that differentness; stigmatization is effective only when the individual internalizes the devaluation (WHO, 2006).

Stigma may present a barrier to participation through reduced opportunities. The WHO (2006) identified stigma as a significant public health challenge and outlined the need for strategies to address stigma and discrimination for those with neurological conditions. Clinicians can address skills that lead to self-advocacy, and work with clients in their communities while educating community workers and the public. For an effective shift in societal norms, stigmatization also needs to be addressed more globally through policy creation and societal initiatives to enhance participation for a range of impairment levels.

With the change in approach from a medical model to a chronic care model, disability should no longer be viewed relative to the individual. Chronic care models shift long term condition management to the individual; there needs to be a reciprocal shift back to the system to view barriers to full participation as public health issues, with corresponding resources to shift public perceptions. The integration of such a 'population health promotion' approach to the management of chronic conditions was advocated by Barr and colleagues (2003) in their Expanded Chronic Care Model. Moreover, as Freedman and colleagues suggest (2012), the evolution of the concept of disability has "highlighted the importance of

participation in meaningful activities as a potential mechanism linking the disablement process to the wellbeing paradigm” (p.588). If individuals living with chronic neurologic conditions are not empowered to reject societal devaluation, it becomes a part of the burden of the condition (WHO, 2006). As such, both societal and individual components of stigma must be addressed – education and strategies to empower the individual, and more global public health policy initiatives to change societal perceptions and alter the devaluating judgments.

5.3 Fatigue management should consistently be assessed and included in rehabilitation programs for those with chronic neurological conditions

Fatigue is a common symptom experienced by people with many neurological conditions (Auduly, 2013; Gadidi et al., 2011; Hammel et al., 2006) and was identified as significant in both the ability and satisfaction models. Higher levels of fatigue appear to create barriers to participation. Functional limitations have been linked to fatigue (Ingles et al., 1999; Maaijwee et al., 2014), and previous work has shown that education interventions (Boosman et al., 2011) and mindfulness -based interventions (Immink, 2014) may be effective at reducing fatigue and improving HRQOL.

Management of fatigue is a common component of self-management programs (Barlow, et al., 2002; Battersby et al., 2009; Lorig et al., 2001), and has been studied as an intervention for some conditions such as MS (Wendebourg et al., 2017).

However, it should be a focus more broadly for rehabilitation programs for those with neurological conditions. Research has demonstrated that group fatigue management programs (Asano et al., 2015; Boosman et al., 2011; Mathiowetz et al., 2005; Sauter et al., 2008), including those offered via tele-health (Finlayson et al., 2011) and on-line (Ghahari and Packer, 2012) formats can be effective at reducing the impact of fatigue. Results of the current study argue for the need to specifically identify, measure and address fatigue as a target of rehabilitation.

5.4 Specifically addressing self- efficacy or patient activation may improve participation outcomes

Self-efficacy and patient activation appear to be related to both satisfaction with and ability to participate, and the final models were equally explanatory whether self-efficacy or patient activation was included. Although these variables are clearly linked, they do not appear to be simply different measures of the same concept, as they are only moderately correlated. Although neither variable contributed a *large* percentage of additional explanation to the models, they were significant in each of the models tested and did improve their accuracy. Further, the addition of either variable decreased the coefficients of the HUI, indicating that targeting activation or self-efficacy may to some degree moderate the effect of impairment on participation outcomes. Investigation of additional variables and/or experimental designs using specifically targeted interventions to address self-efficacy and patient activation might further expose the differences in these two

measures. Despite their potential conceptual differences, the impact on participation appears to be relevant.

Given the associations identified, self-efficacy and/or patient activation appear to provide potential intervention targets for rehabilitation professionals. Further, they might be useful in identifying those at risk for low participation in life roles.

Importantly, both self-efficacy and activation demonstrated low correlations with the HUI, which indicates these could be amenable intervention targets irrespective of the relative impairment level of patients.

Relative to patient activation, addressing and measuring self-efficacy may be more appealing to clinicians. Based on Bandura's social cognitive theory, theoretically derived interventions to address self-efficacy are often the basis for self-management interventions (Packer et al., 2017); interventions based on activation are less well articulated. In addition, the SEMCD measurement tool is freely available, has fewer items, is less time consuming and burdensome to administer, and less complex to score than the PAM.

In both the ability and satisfaction models, the final variable coefficients demonstrate higher values for self-efficacy than PAM. The PAM values in this study ranged from 27 to 100, whereas self-efficacy is a 10point scale, thus it would conceivably be more difficult to achieve a one-unit change on the SEMCD than the PAM; however the relative impact is greater and therefore self-efficacy might be a

worthwhile target for rehabilitation professionals working to enhance participation. Previous work suggests that rehabilitation treatment can improve self-efficacy, even when it is not specifically a treatment focus. When it is specifically addressed, improvements in health status may be even greater (Lorig et al., 2001).

5.5 Summary

Participation was the outcome chosen for examination in this work. It is clear from the results, and consistent with previous evidence, that participation is complex and multifactorial. An important aim of this study was to explore components of participation outside of factors commonly addressed in clinical programs, which could be potential targets for rehabilitation.

Rehabilitation professionals working in the area of neuro-rehabilitation must reach beyond the usual focus on impairment based strategies and explore additional personal and environmental variables that support participation in life roles but have not typically been incorporated. These include: fatigue, support, stigma, and self-efficacy or activation.

5.6 Limitations

The mental health measure used in this study was not significant in the final models with either participation outcome. Multiple previous studies have identified links between mental health and participation (Barclay-Goddard et al., 2012; Cardol et al., 2002; Desrosier et al., 2005; Fairhall et al., 2011; Fallahpour et al., 2011; Law,

2002; Wilkie et al., 2007), so the current findings were surprising. Future work should examine different and/or specific, rather than composite, measures of mental health and how these relate to participation.

In the design of the current study, specific cognitive variables were excluded with the rationale that the subsample included participants with a wide range of conditions spanning congenital, acquired, and progressive conditions such that cognitive components would be quite variable. In addition, awareness and insight can impact the impairment captured in self-reported measures of cognition (Vogel et al., 2004). Impairments in cognition have previously been associated with reduced participation (Adami et al., 2015; Barclay-Goddard et al., 2012; Wilkie et al., 2007). Future research could specifically measure cognitive impairment and examine the relationship of impairments to participation outcomes.

In the regression modeling, the addition of the chosen environmental variables accounted for only an additional approximately 5% of the variation in the models. Future studies could examine a wider range of environmental variables, as previous research has demonstrated that environmental variables may act as significant barriers and facilitators to participation.

This study utilized secondary analysis of a previously collected data set and, as such, the variables included were chosen from a limited number of options. Future research could explore other cognitive, mental health, and functional variables that

might be of interest for this population. Further, the data was drawn from a non-random sample of individuals who responded to the call to participate in the survey, which could limit the generalizability of the results.

The results of this study may be moderated by the scale of the participation measures used, in that the Neuro-QoL measures demonstrated a ceiling at the maximum scores. It is possible that the sample was relatively high functioning compared to the overall population of individuals with neurological conditions, however, given the HUI scores, they did demonstrate a range of impairment. An alternative explanation is that a response shift occurred. Schwartz (2010) suggests that response shifts are “likely to be prevalent in participation measurement because effective coping with disability – whether stable or progressive- would require a regular reappraisal of one’s meaning of participation, relevant experiences to sample, relevant standards to apply, and the relative importance one assigns to the various life domains related to participation” (p.S42).

5.7 Conclusions

The findings of the current study suggest specific targets for rehabilitation for those with chronic neurological conditions. There are differences between participation ability and satisfaction; both are important to address. In addition to addressing impairment, focus should be given to support, fatigue, stigma and self-efficacy or activation.

Rehabilitation professionals working with individuals with chronic neurological conditions should re-consider priorities that are based primarily on impairment reduction strategies and apply more comprehensive approaches that support the complexities of daily living for these individuals. Understanding the roles and activities that are important to the client, and exploring both ability and satisfaction aspects of participation are important in goal-setting and intervention planning. Addressing and reducing impairment has potential to impact both satisfaction and ability participation outcomes, however additional foci should be also incorporated. As outlined earlier, there are limits to the benefits that can be achieved via impairment reduction interventions, and clinicians need to explore multiple aspects of participation when designing strategies to support and enhance participation for those with chronic neurological conditions.

The long- term management of chronic illness occurs in multiple environments and contexts, with both formal and informal supports. Comprehensive client centred practice involves asset-based, collaborative investigation and problem solving tailored to individual client factors that includes both personal and environmental influences. Identifying and limiting the effects of perceived stigma, including considerations for support, and addressing fatigue in clinical treatment will all facilitate participation in life roles for clients with chronic neurological conditions.

The current study is congruent with previous literature consistently demonstrating that participation is multi-factorial and not easily measured or defined. However the

results also suggest factors that could be targets for rehabilitation intervention, but are not yet part of the arsenal clinicians are using in the usual course of rehabilitation for individuals with chronic neurological conditions.

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Appendix A – Table Of Conditions Reported By Survey Respondents

Table 8: Table Of Conditions

Condition	Frequency	Percent
Multiple Sclerosis	163	26.81
Migraine	133	22.20
Brain Injury	100	16.86
Epilepsy	97	15.88
Parkinsons Disease	81	13.26
Muscular Dystrophy	62	10.25
Other Neurological Condition	50	8.10
Spinal Cord Injury	43	7.14
Dystonia	36	6.16
Stroke	35	5.80
Spina Bifida	33	5.40
Hydrocephalus	31	5.11
Other Neuromuscular	30	4.86
ALS	20	3.28
Brain or Spinal Cord Tumour	18	2.96
Cerebral Palsy	13	2.13
Other Neuropsychiatric	11	1.78
Tourettes	7	1.15
Huntingtons Disease	7	1.15
Alzheimers	6	1.00

Appendix B – Access Information For Measures Utilized In Study

1. 6-item Self-Efficacy for Managing Chronic Disease Scale – available from:
[https://www.selfmanagementresource.com/docs/pdfs/English - self-
efficacy for managing chronic disease 6-item.pdf](https://www.selfmanagementresource.com/docs/pdfs/English_-_self-
efficacy_for_managing_chronic_disease_6-item.pdf)
2. Health Utilities Index – licensed use available from:
<http://www.healthutilities.com>
3. Neuro-QoL Scales- available from: [http://www.healthmeasures.net/explore-
measurement-systems/neuro-qol/obtain-and-administer-measures](http://www.healthmeasures.net/explore-
measurement-systems/neuro-qol/obtain-and-administer-measures)
4. Patient Activation Measure – licensed use available from:
<https://www.insigniahealth.com/products/product-licensing>
5. SF-36 – available from:
https://www.rand.org/health/surveys_tools/mos/36-item-short-form.html
Licensed use available from:
[https://campaign.optum.com/content/optum/en/optum-outcomes/what-
we-do/health-surveys.html](https://campaign.optum.com/content/optum/en/optum-outcomes/what-
we-do/health-surveys.html)