Using the International Classification of Functioning, Disability and Health Model to Characterize Body Functions and Structures, Activities and Participation in Physical Activity and the Status of Quality of Life among Individuals with Central Nervous System Lesions

by

Jill A. Dobrinsky
B. A., University of Winnipeg, 2009

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

MASTER OF SCIENCE

in the School of Exercise Science, Physical and Health Education

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Supervisory Committee

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Supervisory Committee

Dr. Viviene A. Temple, (School of Exercise Science, Physical and Health Education)
Co-Supervisor

Dr. Sandra R. Hundza, (School of Exercise Science, Physical and Health Education)
Co-Supervisor

Dr. Joan Wharf-Higgins (School of Exercise Science, Physical and Health Education)
Departmental Member
Abstract

Regular physical activity is significant for overall health and can reduce the risk of chronic disease and health related conditions. Individuals with central nervous system CNS lesions experience impairments that limit their participation in physical activity and reduce quality of life; therefore it is even more important to understand the relationship between the barriers and affordances to engaging in physical activity for this cohort. The current study has uniquely identified a population (n= 11) based on the common experience of spasticity in the lower limb resulting from a CNS lesion across multiple diagnostic categories and used the International Classification of Functioning, Disability and Health model (ICF) (WHO, 2001) to characterize the impairments in body structure and functions, activities and contextual factors to better understand their influence on physical activity levels in this cohort. The findings showed that each individual experienced physical impairments for multiple body functions and structures comprising reduced ankle range of motion (M= 9.98 PlantarFlexion), spasticity as measured by the Ankle Plantar Flexor Tone Scale (middle ankle range resistance M= 1.56, stretch reflex M= 1.64) as well as some reports of pain on a Visual Analog Scale (Usual, M =1.10, and Worst pain, M= 1.64). On average the cohort presented with mild to moderate impairments in their mobility as measured by Timed Up and Go (M= 28.28 seconds), walking velocity (M= 74.94cm/sec Gaitrite mat) and falls (M=.91). Findings from both the Physical Survey for Individuals with Physical Disabilities (PASIPD) and semi-structured interviews suggest that participation in physical activity was low across life roles including areas of work and employment, recreation and leisure, domestic life and selfcare. The physical component summary (PCS) scores of the Short-Form 36 Version 2 Quality of life Survey were lower than average norms (M=38.12, SD=7.53), while the mental components summary (MCS) scores were on par with average ranges (M=50.61, SD=10.02); however the overall MCS score was slightly
higher than the trend reflected in the mental health sub-scores which ranged from between slightly below average to average. Clearly aligning with the ICF model, the volume and intensity of physical activity was hampered by physical impairments, fear of falling, cost of activities, poor weather, a lack of transportation, and cut backs to services as reported in the semi-structured interviews. However, the quantitative relationships between the domains of the ICF were less obvious. Through qualitative interviews the participants’ positive outlook toward participating in life roles was strongly expressed. Despite barriers, individuals were finding ways to be somewhat active and were motivated to do more and overcome their functional limitations.
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Acknowledgements

I would like to take this opportunity to thank the people who have contributed to this research and to the completion of my Masters degree. I would like to thank my supervisors Dr. Sandra Hundza and Dr. Viviene Temple for their guidance, expertise, knowledge and support throughout my graduate program. Thank you so much for your contribution, advice and feedback throughout this process. I would also like to thank Dr. Joan Wharf-Higgins for your feedback and valued perspective on this research topic. Additionally, I would like to thank the administrative, clinical and professional staff at the Vancouver Island Health Authorities Spasticity Clinic for granting me with the opportunity to conduct research in their facility.

At this time I would also like to thank the University of Victoria Honors students from the School of Exercise Science, Physical and Health Education, Kim Choy, Brayley Chow, Iris Loots, and Jasmine Kim who helped collect, enter, and interpret data for this research study. A big appreciation to the participants of the study who had the patience, took the time and, effort to participate, as well as demonstrate significant motivation and interest in the process of the research study.

Finally, I would like to thank my close friends and family for their assistance, encouraging words and support towards my academic pursuits. Thank you all.
Dedication

This thesis is dedicated to my father, Brian Dobrinsky and my mother, Sonia Matwyczuk, the two people in my life who have helped make all my goals and dreams achievable. My academic success could have not been possible without your unconditional support, knowledge, strength and encouragement along the way. You two always believed in me no matter what and guided my path to success. You two have inspired me throughout my entire life and I cannot thank the two of you enough and I am very grateful.

My research is dedicated to individuals with disabilities and the findings of my research will be used to improve their life roles, improve quality of life and increase participation in physical activity. Specifically, I was inspired by a close friend of mine to pursue a field in rehabilitation and disability because I watched him for years suffer with illness and was non-ambulatory. I wanted to learn more about his condition as well as what I could do to help him and others with disabilities. To announce with deep sadness that he passed on (August 22nd, 2011), however, earlier this month was so proud to congratulate me on the completion of my Masters degree.
Chapter 1: Introduction

Physical activity is defined as any musculoskeletal movement produced by skeletal muscles that require energy expenditure (World Health Organization, 2011). Regular physical activity can reduce the risk of chronic disease and health related conditions (Cameron, Craig, & Paolin, 2005). Conversely physical inactivity and the secondary negative health conditions associated with inactivity are among the leading cause of premature death, with a prevalence of 3.2 million deaths globally (WHO, 2011). Individuals with disabilities, including those resulting from central nervous system (CNS) lesions experience greater difficulties engaging in physical activity due to the limitations in mobility (Carroll, Leiser, & Paisley, 2006), which leads to sedentary lifestyles (Calota & Levin, 2009; Lechner, Frotzler, & Eser, 2006; Rousseaux, Kozlowski, & Froger, 2002; Skold, Levi, & Seiger, 1999). Individuals with CNS lesions are less likely to participate in physical activity due to social, emotional and physical barriers they face as a result of their impairment (Carroll et al., 2006). These social, emotional and physical barriers not only limit participation in physical activity, they also influence perceived quality of life (QOL). Thus understanding the physical activity levels and barriers to participating in physical activity for individuals with disability is more urgent than exploring physical activity for those of the general public because individuals with disability are more likely to lose their independence and experience secondary negative health outcomes associated with inactivity (Rimmer, 2005). Further understanding ways to enhance physical activity levels in those with disabilities will reduce these associated conditions, and improve health outcomes and quality of life.

A CNS lesion, such as stroke, cerebral palsy (CP) or multiple sclerosis (MS), can lead to imbalances of the motor neuron activity. This results in a decrease in inhibition and a resulting increase in excitation of motor neurons, characterized by hyperactivity, resulting in increased ‘muscle tone’ in some muscles (Adams & Hicks, 2005; Mayer & Esquenazi, 2003). This increased muscle tone and altered reflex control results in spasticity. Spasticity is prevalent after stroke and with CP and MS (Di Fabio, Soderberg, Choi, Hansen, & Schapiro, 1998; Koritsas & Iacono, 2009; Sommerfeld, Eek, Svensson, Holmqvist, & Von Arbin, 2004). If spasticity is not well managed it can cause pain,
negatively affect mobility, physical activity and QOL, increase dependent behaviour as well as contribute to secondary health conditions and mortality (Calota & Levin, 2009; Lechner et al., 2006; Rousseaux et al., 2002; & Skold et al., 1999).

Previous research has characterized physical activity levels within specific clinical populations (Gordon et al., 2004; Tudor-Locke & Myers, 2001); however previous work has not directly linked the impairments in body structure and functions, activities and personal or environment barriers to the levels of participation in physical activity. The current study is unique in that it identifies a population based on the common experience of spasticity in the lower limb resulting from an CNS lesion across multiple diagnostic categories and used the International Classification of Functioning, Disability and Health model (ICF) (WHO, 2001) to characterize the impairments in body structure and functions, activities and contextual factors to better understand their influence on physical activity levels in this cohort.

The ICF is a model developed by the World Health Organization (WHO) (2001) that identifies how performance in a standard and usual environment is affected by changes in body function and structure as a result of a health condition (WHO, 2002). Further the relationship between physical activity levels and quality of life was explored in this cohort. Describing impairments in individuals recovering from stroke, or who have MS or CP as a group with a common condition is a unique approach. Characterizing the impairments, status of physical activity, and personal and environmental barriers experienced by this population which limit their participation in physical activity will provide insight into the individual’s level of health. This improved understanding will provide policy makers, health care professionals and community leaders with knowledge and evidence to inform policy and practice to better accommodate the needs of individuals with disabilities to facilitate their participation in physical activity.

**Purpose**

The aim of the study is to better understand the influence of body structures and functions, activities and contextual factors on participation in physical activity in those
with a CNS lesion resulting in lower limb spasticity. An additional aim is to better understand the interaction between participation in physical activity and QOL.

**Research Questions**

1. For individuals with CNS lesions and resulting spasticity in the lower limb:
   a. What are their physical activity levels?
   b. What are their body functions and structures and activities?
   c. What is their perceived health-related QOL?

2. What is the relationship between:
   a. Contextual factors, both environmental and personal, and participation in physical activity?
   b. Body function and structures and activities and participation in physical activity?
   c. Body functions and structures and activities and health related QOL?
   d. Participation in physical activity and health-related QOL?

**Operational Definitions**

Health-related QOL: The overall mental and physical well-being of an individual at an individual level. In this study physical and mental health is measured via self-report across eight health domains: physical functioning, mental health, vitality, emotional roles, physical roles, bodily pain, social functioning, and general health.

Physical activity: In this study, physical activity is defined as the level of physical engagement in leisure, work and household activities

**List of Acronyms**

Multiple Sclerosis: MS

Cerebral Palsy: CP

Vancouver Island Health Authorities: VIHA
Delimitations

Cohort was delimited to those with CNS lesions resulting in spasticity of the lower extremity.

Limitations

A limitation to this study is that its population was seeking therapy for their health condition and may have been more motivated among those of the general public with
CNS lesions. Another limitation to this study was the size of sample, which included eleven participants.
Chapter 2: Review of Literature

Physical activity can make an important contribution to QOL. People with neurological conditions experience lower levels of physical activity associated with increased barriers to participation. In the context of the WHO model of ICF, this review will describe the current evidence of physical activity levels of adults with neurological conditions that involve CNS lesions, the barriers to participation in physical activity, and the benefits of being active including improved QOL. Further this review will characterize the body functions and structures with CNS lesions and associated spasticity and review the evidence of its relationship to physical activity levels.

Central Nervous System Lesion - prevalence and incidence

Stroke, CP and MS are neurological conditions that result from lesions to the CNS including lesions to the upper motor neurons (UMN). More than 50,000 people experience stroke in Canada each year and about 300,000 Canadians are living with the effects of stroke (Heart and Stroke Foundation, 2010). Of those who survive, 25% have minor impairment or disability, 40% have a moderate to severe impairment, and a further 10% require long-term care due to the severity of their condition (Heart and Stroke Foundation, 2010). In Canada, CP is a common developmental neurological condition, with an estimated prevalence of 2.57 per 1000 births (Robertson, Svenson, & Joffres, 1998) or 16 per 1000 among those born prematurely (Robertson, Watt, & Yasui, 2007). Another neurological condition involving a lesion to the CNS is MS and is prevalent in approximately 55,000-75,000 Canadians. Approximately 1,000 new cases of MS are diagnosed in Canada each year (Multiple Sclerosis Society of Canada, 2011).

Altered motor function is a common impairment in those who recover from stroke and who live with CP and MS (Koritsas & Iacono, 2009; Kraft & Brown, 2007; Sommerfeld et al., 2004). This motor impairment significantly limits life participation and independence and leads to disability (Levi, Hultling, & Seiger, 1995; Skold et al., 1999; Rousseaux et al., 2002). Often impairments lead to loss of function and sedentary behaviours that may contribute to secondary related health conditions (i.e. obesity) (Rousseaux et al., 2002). Therefore, it is important to understand the barriers to participating in physical activity that this population experiences.
What is an Upper Motor Neuron Lesion and Spasticity and How do they Lead to Disability?

An UMN lesion is a lesion within the CNS that leads to alterations in the neural control. There is hypoactivity of some motor neurons and hyperactivity in other motor neurons resulting from alterations in the balance of inhibitory and excitatory inputs onto the motor neurons. Hyperactivity results in increased ‘muscle tone’ (Adams & Hicks, 2005; Mayer & Esquenazi, 2003). Spasticity is associated with increased muscle tone and is a common neuromuscular clinical feature resulting from a lesion to the CNS (Calota & Levin, 2009; Lechner, Frotzler, & Eser, 2006; Rousseaux et al., 2002 & Skold et al., 1999). Spasticity results from an increased excitation and decreased inhibition of the motor neurons (Adams & Hicks, 2005). The most commonly cited definition for spasticity is that published by Lance (1980): Spasticity is a motor disorder associated with a velocity dependent increase in tonic stretch reflex (muscle tone) with exaggerated tendon jerks, resulting from increased motor activity of the stretch reflex. Altered reflex control is a key component of spasticity (Whitlock, 1990). Spasticity is prevalent in those who recover from stroke and who live with CP and MS (Koritsas & Iacono, 2009; Kraft & Brown, 2007; O’Brien, 2002; Sommerfeld, Eek, Svensson, Holmqvist, & Von Arbin, 2004). Spasticity negatively affects QOL through limiting activities of daily living (ADL); impairs mobility; causes pain, sleep disturbance, and has negative implications with self-care, self-esteem and body image (Ward, 2003; Bhakta, 2000).

Physical Activity in Individuals with CNS Lesions and Spasticity

The Healthy People 2010 report states that in 1997 less than 12% of U.S. adults with disabilities participated in moderate physical activity less than 5 days a week (US Department of Health and Human Services, 2010). In Canada, 56% of adults living with disabilities are physically inactive (Statistics Canada, 2001). Individuals with CP, MS, and those recovering from a stroke are very inactive and are at risk of secondary health conditions. A study published by Heller, Ying, Rimmer, and Marks (2002) investigated the levels of physical activity among individuals with CP and found that 50% of them participated in some type of exercise averaging 1.6 days a week. The literature reports that most adults with CP did not achieve the recommended minimum of 30 minutes of
moderate physical activity a day (Gaskin & Morris, 2008; Nieuwenhuijsen et al., 2009). MS is associated with various symptoms such as weakness and spasticity that restrict participation in physical activity. For example, Stuifbergen and Roberts (1997) found that only 22% of individuals with MS participated in light to moderate leisure exercise. Individuals who have experienced a stroke are predisposed to sedentary lifestyles and low levels of physical activity (Thorpe, 2009). A study investigated individuals with chronic conditions including those who have recovered from a stroke and found that they participated less than the recommended 1,000 kcal of physical activity per week (Sawatzky, Liu-Ambrose, Miller, & Marra, 2007).

Physical activity can be limited or non-existent for individuals with disabling conditions because of the barriers associated with impairments (Carroll et al., 2006). They are less likely to participate in physical activity due to social, emotional and physical barriers they face as a result of their impairment (Carroll et al., 2006) such as poor weather, immobility, and pain. Thus impairments limit the participation of those with disability leading to sedentary lifestyles (Calota & Levin, 2009; Lechner et al., 2006; Rousseaux et al., 2002; & Skold et al., 1999).

In those with disabling conditions, inactive lifestyles put them at higher risk for poor overall health and leads to secondary health conditions. These inactive lifestyles may lead to chronic disorders such as: respiratory disorders (asthma, chronic bronchitis, emphysema or chronic obstructive pulmonary disease), musculoskeletal disorders (arthritis, fibromyalgia or back problems), cardiovascular disorders (high blood pressure or heart disease), diabetes, urinary or bowel problems urinary incontinence, and Crohn's disease or colitis (Kayes, McPherson, Taylor, Schluter, Wilson, & Kolt, 2007; Sawatzky et al., 2007; Sommerfeld et al., 2006). In the literature, individuals who have CNS lesions and spasticity have been found to participate less in physical activity due to negative symptoms such as, contractures, abnormal limb movement, pain, clonus, muscle stiffness and repetitive spasms (Bhakta, 2000; O’Brien, 2002; Sommerfeld et al., 2003). Individuals with CP experience greater difficulties engaging in physical activity due to decrease in functional and physiological movement required for performing ADL (Carroll et al., 2006). Ultimately, inactivity and sedentary lifestyles are the leading causes of death among individuals with disabling conditions (Carroll et al., 2006).
In addition to inactive lifestyles, individuals with MS, CP and post stroke are more likely to experience a reduction in QOL (Lim & Wong, 2009; Lynch et al., 2008; Sawatzky et al., 2007). Spasticity limits effective walking and self-care, causes pain and fatigue, as well as disturbs sleep (Adams & Hicks, 2005). These impairments in body systems and functions are associated with decreased mobility, an increase in dependent behaviour, and decreased ability to carry out ADL’s, such as, hygiene, cooking, dressing, cleaning, laundry and compromised safety (Adams & Hicks, 2005; Bhakta et al., 1996; Welmer, Arbin, Holmqvist, & Sommerfeld, 2006). Therefore, these impairments, particularly immobility, affect many facets of life and one’s ability to participate in society which negatively impacts health and QOL (Adams & Hicks, 2005).

Much research in the last decade has been dedicated to examining the benefits of physical activity for individuals with disabilities (van der Ploeg et al., 2004). Regular physical activity can help reduce the functional restrictions experienced by individuals with disabilities (van der Ploeg et al., 2004). Regular physical activity can improve overall health therefore increase independence and reduce any assistance that they may need to perform ADL (e.g. strength, balance and flexibility) (Rimmer, 1999). Exploring the benefits of physical activity for individuals with disabling conditions is urgent as they are more likely to lose their independence and experience a regression in health than the general population (Rimmer, 2005; van der Ploeg et al., 2004).

**Barriers to Being Active**

Disability is an interaction between the impairment and the context. Individuals with motor impairment tend to have restrictions in ADL which further contribute to inactive lifestyles (Calota & Levin, 2009; Lechner et al., 2006; Rousseaux et al., 2002; Skold et al., 1999). Twenty-five to fifty percent of individuals who survive a stroke require at least some assistance with ADL (Gordon, et al., 2004). It is important to understand the barriers associated with their condition. An understanding of these barriers will be gained through understanding the interaction between the condition and the environmental and personal contexts. This understanding will help inform processes to address these barriers and improve participation in physical activity and enhance QOL. If this interaction is not understood there can be negative effects on QOL and potential to
life-threatening consequences (Calota & Levin, 2009; Lechner et al., 2006; Rousseaux et al., 2002; Skold et al., 1999).

**Barriers and Facilitators to Participation in Physical Activity**

Individuals with CNS lesions face barriers that restrict their participation in physical activity. Previous work has identified that poor health conditions are the greatest barrier to participation (Rimmer, Wang, & Smith, 2008; van der Ploeg et al., 2004). Along with barriers there are facilitators which enhance participation in physical activity. As with other Canadians, both barriers and facilitators contribute to physical activity patterns in this population.

**Built and Natural Environmental Barriers/Facilitators**

Inaccessible facilities pose a built environmental barrier to participation in physical activity for individuals with disabilities (Rimmer et al., 2004; van der Ploeg et al., 2004). Built environmental barriers such as poor street conditions and heavy traffic limit mobility, specifically for individuals with lower extremity impairment (Balfour & Kaplan, 2002; Clarke, Ailshire, Bader, Morenoff, & House, 2008). Clarke et al. (2008) investigated mobility impairments of the lower extremities and found that poor lower balance and low extremity strength led to a decline in mobility for individuals who lived in poor built environments. Wheelchair users experienced barriers such as narrow sidewalks, no curb cuts, blocked curbs, inaccessible doorways and bathrooms, no ramps, steep ramps, high counter tops and no parking (Rimmer et al., 2004). In contrast, optimal access to facilities is associated with enhanced participation for individuals with disabling conditions (van der Ploeg et al., 2004). Natural environmental barriers, such as the weather and season restricted participation in physical activity (Rimmer et al., 2004; van der Ploeg et al., 2004). Individuals state that slippery sidewalks, trails and roads due to snow, rain and/or ice were restricting factors. Moreover, these environmental barriers led to secondary barriers of safety with concerns due to the ultimate fear of falling. Therefore, self-efficacy, confidence and fear were personal barriers associated with environmental conditions (van der Ploeg et al., 2004).
Emotional and Psychological Barriers/Facilitators

Individuals with disabling conditions are more likely to experience fatigue, low intrinsic motivation, self-efficacy and mood, difficulty with coping skills and adaptability, cognitive and learning ability and, lack of energy, time and independence (Gordon et al., 2004; Rimmer et al., 2004; Rimmer & Hedman, 1998; van der Ploeg et al., 2004). According to Gordon et al. (2004), individual’s physical limitations resulting from stroke lead to a decline in social interaction as well as withdrawal, which in turn can lead to depression and inactivity. Depression is prevalent in 16-68% of individuals post stroke and a barrier to their health and well-being (Gresham & Stason, 1998). Individuals who are socially withdrawn are less likely to leave their home and therefore, less likely to attend public facilities that offer physical activity equipment and/or programs. Emotional and psychological facilitators include, positive peer support from family, friends and therapists. A significant or beneficial facilitator was having access to rehabilitation professionals and programs which helped individuals substantially with motivation (Rimmer et al., 2004; van der Ploeg et al., 2004). However, individuals who did not have access to therapy and community programs reported that not knowing where or how to exercise was a barrier (Rimmer & Hedman, 1998; Rimmer et al., 2008).

Social Attitude Barriers

A barrier to participation among individuals with disabilities are the negative attitudes of individuals without disabilities (Rimmer at al., 2004; US Department of Health and Human Services, 2010; van der Ploeg et al., 2004). Individuals themselves experienced negative attitudes towards physical activity, assuming that physical activity would exacerbate their condition or that physical activity would not improve their condition (Rimmer et al., 2008). Individuals reported that they felt self-conscious about needing and requesting assistance and visiting public facilities (Rimmer et al., 2004). Some individuals lacked support from friends and family and felt it was difficult to attend facilities alone, especially feeling that some facility attendants were not trained to address their needs (Rimmer et al., 2004; Rimmer et al., 2008). Many individuals perceived that the facilities’ environments were unfriendly (Rimmer et al., 2004).
Economic and Cost Barriers/Facilitators

The majority of individuals report that one of the greatest barriers to physical activity was lack of and/or cost of transportation and the cost of memberships and programs because individuals with disability claim fixed incomes and cannot afford the cost associated with groups, programs and activities (Rimmer et al., 2004; Rimmer & Hedman, 1998). Along with the cost of transportation, individuals with disabilities are less likely to use public transportation because they have little energy or desire to get out of the house and take public transportation (Rimmer & Hedman, 1998). Facilitating factors include subsidies to make public recreation facilities more affordable (Rimmer et al., 2004) and transportation by friends and family members (van der Ploeg, et al., 2004). This form of support assists with access to and from facilities and removes the cost of public transportation.

Equipment Barriers/Facilitators

Some individuals reported that they had access to exercise equipment either at home or public facilities (Rimmer et al., 2004; van der Ploeg et al., 2004). Individuals with disabling conditions reported that most pool facilities had chairs to lift them in and out of the pool. Aquatic activity is a common therapeutic method prescribed to individuals with disabilities (Rimmer et al., 2004). Despite the access to exercise equipment, individuals with disabling conditions reported that a lack of space between the equipment and a lack of adaptive equipment were barriers when attending public facilities (Rimmer et al., 2004). However, not all individuals had access to facilities and/or equipment to accommodate their needs (van der Ploeg et al., 2004). According to Gordon et al. (2004), stroke patients who experienced social withdrawal were more disadvantaged because they did not have the proper equipment in their homes to sustain exercise/activity programs.

Components of the ICF model

The ICF is a model developed by the WHO (2001) that identifies how performance in a standard and usual environment is affected by changes in body function
and structure as a result of a health condition (WHO, 2002). The ICF model is an etiological framework that concentrates on the individual’s level of health, thereby, acknowledging disability as a universal human experience. The ICF model provides a common language to facilitate communication, clinical practice and patient care to accommodate individual needs (Dahl, 2002). The ICF model develops a complete view on disability which in turn can facilitate healthy behaviours.

The ICF model (see Figure) consists of two parts. Part one outlines the components of functioning and disability; and part two describes their interactions with the contextual factors (WHO, 2001). Part one is divided into three domains of human functioning: 1) body structures and functions, 2) activity and, 3) participation. These domains can be used to classify the outcome of health. Part two outlines the contextual factors of personal and environmental conditions. This model is used to understand how body functions and structures, activity and participation interact with each other and how they are influenced by environment and personal conditions (Harris, MacDermid, & Roth, 2005; WHO, 2003). The model uses the term functioning to describe all body functions and structures and the performance of activities and participation in communal life (Simeonssson et al., 2003). The WHO (2002, p. 3) defines disability as “an umbrella term for impairments, activity limitations and participation restrictions”. The ICF model uses the interaction of disability and functioning to view outcomes of interactions between health conditions and the contextual factors outlined in this model (WHO, 2002). The ICF model uses all domains to capture a complete view of the human experience when living with a disability. To further understand how significant this model is for implementing healthy practice each domain of the model is investigated further.
Figure 1. Components of ICF Model

(World Health Organization, 2002).

As displayed in Figure 1, the first component of the ICF model is body functions and structures. This domain describes how health conditions such as disease, disorders or illness impact an individual’s body structure and function (Jette, 2009; Masala & Petretto, 2011; Steiner et al., 2002). Body structures are anatomical parts of the body and represent the limbs and organs (WHO, 2002). Body functions are defined as the physiological function of body systems (WHO, 2002). Body structures and functions such as: the nervous system, ear, eyes, voice, speech, respiratory, digestive, metabolic, and structures related to movement and skin, can all be susceptible to impairment. Problems in body structures and functions lead to restrictions that are due to significant loss or deviation in human function (Jette, 2009). Health conditions can result in deficits in the anatomical structures and human physiology. These deficits can cause problems such as: pain, weakness and loss of hearing and contribute to loss of human function in which can further lead to sedentary lifestyles. This component of the ICF model can be used to characterize the limitations in body structures and functions of individuals to further understand the barriers they encounter.

The ICF uses both the domain of activity and participation to describe how human functioning is effected at an individual (activity) and societal (participation) level. Activity, the second component, is defined by WHO (2001), as the execution of a task or
action by an individual. This domain describes the individual’s perspective on functioning and how disability affects the execution of a task. Health conditions can lead to difficulties executing tasks and therefore lead to sedentary lifestyles (Jette, 2006). According to the WHO/Economic and Social Commission for Asia and the Pacific (ESCAP) training manual (2008) on disability, limitations in activity can range from minor to major deviations in events associated with quality or quantity of a task.

Participation, the third component, is defined as “involvement in a life situation” (WHO, 2001, p. 3), and focuses on a person’s QOL and well-being (Noonan et al., 2009). However, health conditions may restrict participation and individuals may experience difficulty engaging in roles and activities such as: working for pay, joining in community activities or grand-parenting. It is important to identify why and how the roles and activities for individuals with disabilities are difficult by identifying how the impairment restricts participation. According to the WHO/ESCAP Training Manual on Disability (2008), people with the same impairment experience different levels of incapacities and restrictions in performing ADL. It is easier to implement resources to improve health in individuals with disabilities if the conditions of the impairment are understood. According to Noonan et al. (2009), reducing disability is a significant rehabilitation outcome for improving health. A reduction in disability will improve life participation and ultimately, lead to a more active lifestyle (Noonan et al., 2009). Participation and activities include the following: learning and applying knowledge, communication, mobility, self care, domestic life responsibilities, interpersonal relationships and community, social and civil life (WHO, 2002).

Part two of the ICF model consists of contextual factors; both environmental and personal. Environment is defined as “physical, social and attitudinal environment in which people live and conduct their lives” (WHO, 2002, p.10). Environmental factors are external to the individual’s condition and can be represented by social attitudes, architectural characteristics, legal and social structures as well as climate and terrain (WHO, 2001; 2002; Jette, 2009). The ICF identifies how products and technology, natural environment and human-made changes to the environment, support and relationships, attitudes, services, systems and policies may inhibit or facilitate function and disability (WHO, 2001; 2002). The ICF model distinguishes between disability,
function and environment. With this distinction health professionals are able to acquire information to implement resources, and, thus improve health outcomes. For example, improve access to health care facilities by building ramps and elevators, address communication barriers for the deaf, and improve policy access to medical coverage (Lollar, 2002). Alterations in environments made to accommodate the needs for individuals with disabling conditions can reduce or alleviate impairment (Masala & Petretto, 2011). When health is compromised by environmental factors it may restrict activity and participation and, ultimately lead to poor health behaviours.

Another contextual factor identified in the ICF model is personal factors. Personal factors are defined as individual features independent to health conditions or health status (Jette, 2009). Personal factors include, gender, race, age, fitness, lifestyle, habits, upbringing, education, coping styles, social background, past and current experiences, character style and other traits that influence how disability is perceived by the individual (Jette, 2009; WHO, 2002). Separate from the individual’s health condition, it is important to identify personal traits that may contribute to health outcomes. Along with the other ICF domains, personal factors can contribute information for implementing optimal rehabilitation strategies to enhance QOL and health outcomes. Moreover, to help characterize personal factors of individuals with disabilities that result in barriers to participation.

Qualifying and Quantifying Components of the ICF relative to Mobility and CNS Lesions

Given the breadth of classifications within each component of the ICF, this section of the literature review has been limited to measures specific to body functions and structures as well activities and participation as they relate to mobility and QOL of adults with CNS lesions. These measures were identified as key characteristics common to those who experience spasticity in the lower limb resulting from CNS lesion and appropriately characterize the impairments in body structure and functions, activities and contextual factors to better understand their influence on physical activity levels in this cohort. By exploring relationships between these measures a better understanding of the interactions between participation in physical activity and quality of life can be
determined. The areas of focus for this study within each domain of the ICF are illustrated in Figure 2.

Figure 2. *Measures of focus within each domain of the ICF model related to mobility and CNS lesions*

**Body Functions and Structures**

*Ankle Range of Motion (ROM)*

Active ankle ROM is the degree of movement at the joint and it can be measured using a gonimeter (Appendix A). This outcome measure has been used for research and clinical purpose for measuring ROM in individuals with neurological conditions involving spasticity (Fleuren, Snoek, Voerman, & Hermens, 2009; Gonzalex, Sepulveda, Reyes, Ramirez, & Arango, 1994; Hurvitz, Conti, & Brown, 2003; Hu, Chuang, Lui, Chien, Chen, & Chen, 2009). This assessment reports high inter-intra reliability, ranging from 0.88-0.97 (Boone, Azen, Lin, Spence, Baron, & Lee, 1978; Low, 1978; Rothstein, Miller, & Roettger, 1983; Salter, 1955).
Spasticity and Clonus

Spasticity is a symptom of CNS lesion causing an increase in motor neuron excitation. Motor neuron excitation is characterized by hyperactivity, resulting in obvious ‘muscle tone’ or ‘muscle stiffness’ (Sommefeld et al., 2003). Spasticity results in increased excitation and decreased inhibition of the motor neurons (Adams & Hicks, 2005). Moreover, spasticity causes an imbalance of inhibitory and excitatory motor activity responsible for voluntary and involuntary human movement. This imbalance in neural activity causes disability via motor impairment (Adams & Hicks, 2005). Clonus is a component of spasticity and results in a rhythmic pattern of contractions due to the alternate stretching and unloading of the muscle spindles in spastic muscles (Purves et al., 2001). Clonus may impair foot placement and directly effect walking and standing (Bhakta, 2000). Ankle Plantar Flexors Tone Scale (APFTS) (Appendix B), constructed by Takeuchi, Kuwabara and Usuda (2009) is used to measure spasticity and clonus at the ankle plantar flexors. The APFTS reports high inter-rater reliability scores between .72 to .94. Intrarater reliability also scored high between .63 - .82. Clonus can also be quantified by counting the beats of contractions.

Cognitive Function

Cognitive functioning is defined as an individual’s ability to register, perceive, store, retrieve and apply information (Foreman, Fletcher, Mion, & Trygstald, 2003). The Mini Mental State Evaluation (MMSE) (Appendix C) (Folstein & Luria, 1973) is used to assess cognitive functioning. This exam evaluates orientation, registration, recall, attention and calculation, language, following directions, perception and judgment. A review on the MMSE found test-retest reliabilities ranging from .80 to .95 (Anthony, LeResche, Niaz, von Korff, & Folstein, 1982; Dick, Guiloff, Stewart, Blackstock, Bielawska, & Paul, 1984; Molloy, Alemayehu, & Roberts, 1991; Tombaugh & McIntyre, 1992).

Pain

Pain is often experienced by individuals post stroke, with CP and MS. Pain is often secondary soft tissue injury resulting indirectly from motor impairments. Although,
there are numerous scales to assess pain, the Visual Analogue Scale (VAS) (Appendix D) is a subjective measure that has been successful in evaluating the level and location of pain in individuals with lower limb spasticity (Berthier, Potel, Leconte, Touze, & Baron, 1998; Khodairy, Gobelet, & Rossier, 1998; Mancini, Sandrini, Moglia, Nappi, & Pacchetti, 2005; Miscio et al., 2004; Pierson, Katz, & Tarsy, 1996; Suputtitada, 2002). This instrument is quick and easy to administer (Berthier et al., 1998; Suputtitada, 2002). The VAS is widely used and has moderate validity ($r = .62$) (Gloth, Scheve, Stober, Chow, & Prosser, 2001) and high test-retest reliability ranges between .71 and .99 (Ahles, Ruckdeschel, & Blanchard, 1984; Huskisson, 1974; Ferraz, Quaresma, Aquina, Atra, Tugwell, & Goldsmith, 1990).

**Activities**

**Functional Mobility**

Functional mobility is the capacity to perform a given function or activity (Margaret, 2000). An assessment used to measure functional mobility is the Timed Up and Go (TUG) (Appendix E) test (Podsiadlo & Richardson, 1991). This tool was developed by Marthias et al. (1986) and designed to evaluate the risk of falls based on mobility, balance and locomotion performance in individuals with disabilities. Shumway-Cook et al. (2000) established a cut off value of 14 seconds or less, if the individual achieved this value their walking was functional and were at low risk of falling. This assessment has been applied to individuals with Parkinson’s Disease (Morris, Morris, & Iansek, 2001) and cerebral vascular damage (Freter & Fruchter, 2000); and older adults with or without cognitive impairment (Rockwood, Awalt, Carver, & MacKnight, 2000), as well as de-conditioned older adults (Podsiadlo & Richardson, 1991). The TUG is an objective measure used to evaluate functional ability in individuals with disabilities (Mathias, Nayak, & Isaacs, 1986; Podsiadlo, & Richardson, 1991; Rockwood et al., 2000; Shumway-Cook, Brauer, & Woolacott, 2000). This measure reports high intra-rater reliability scores of 0.92 and 0.99 (Podsiadlo & Richardson, 1991; Rockwood et al., 2000; Schoppen et al., 1999). However, Rockwood et al. (2000) questioned the test-retest reliability because their study established a moderate interclass correlation (ICC) score of 0.56 for people with cognitive impairment and .50 for people without cognitive
impairment. Nordin and colleagues (2006) purposed that the poor design of having extended periods between testing (eg: 72-122 days) was responsible for Rockwood and colleagues poor reliability score (Nordin et al., 2006). Nordin and colleagues (2006) found a relative reliability between test sessions reached ICC scores of .92 and .91 for interrater and interrater measurements, respectively (Nordin et al., 2006); however they also found wide range of variability within and between raters and suggested that clinicians should be aware of such variability before interpreting TUG scores for individuals.

**Gait**

Gait is a manner of walking performed by the individual’s lower limbs and has many components that are characteristic for different health conditions. For this reasons components such as velocity, stride length and time, stride width to mention a few are routinely measured. Measuring spatio-temporal gait parameters is a successful method for analyzing gait mechanics for individuals with disabilities. These measures can provide insight on how an individual’s impairment affects their overall level of activity including performance in ADL’s. Spatio-temporal gait parameters have been successfully measured using the GAITrite pressure sensing mat (Bilney, Morris, & Webster, 2003) (Appendix F). Gait measurements report strong concurrent validity (McDonough et al., 2001) and test retest reliability (ICC scores of 0.96) (van Uden, & Besser, 2004).

**Fall Occurrences**

Accidental falls are common among individuals living with MS (Nilsagard, Lundholm, Denison, & Gunnarsson, 2009), chronic stoke (Harris et al., 2005) or CP (Smith & Bagley, 2010). Providing a broad definition of a fall reduces underreporting of falls due to participant’s varying beliefs on what constitutes a fall. Further classification of falls can then be made based on circumstances such as location, activity, and cause. Hauer and colleagues (2006) suggest that in order to avoid researcher bias in misclassifying a fall, a technical definition of falls should be used and more than one member of the research team should review the fall reports (Hauer, Lamb, Jorstad, Todd, & Becker, 2006). A fall is defined 'as “an event, which results in a person coming to rest
inadvertently on the ground or other lower level” (Wolf, et al., 1996). Falls are dangerous and can have significant health implications such as a fractured hip that can affect mobility and self-confidence and even result in death (Gietzelt et al., 2009). Monitoring falls is an effective way to measure the efficacy of interventions that may influence the incidence of falls (Appendix G) (Campbell, Robertson, & Gardner, 1997; Close, Ellis, & Hooper, 1999; Hornebrook, Stevens, & Wingfield, 1994; Rubenstein, Josephson, & Robbins, 1994). Fall recall assessments are successful in monitoring falls with high validity and reliability ($r = 0.79 – 0.95$) (Mackenzie, Byles, & D’Este, 2006; Rubenstein, Josephson, & Robbins, 1994; Schmidt, 1989; Wolf et al., 2003). Falls can be recorded using a prospective calendar or diary recording, retrospective recall, or a combination of both. The prospective method has been found to be more accurate than retrospective self-reporting of falls. Retrospective methods resulted in under-reporting fall events which worsened as the time between follow-ups increased (Mackenzie et al., 2006). It is recommended that in addition to using prospective daily recording, a telephone or face-to-face follow-up at least once per month be incorporated (Hauer et al., 2006).

**Participation**

*Physical Activity*

Physical activity involves any bodily movement produced by the skeletal system that requires energy expenditure. The Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) (Appendix H) (Washburn, Zhu, McAuley, Frogley, & Figoni, 2002) was developed to evaluate the following 5 domains: 1) Occupation/Transportation 2) Home Repairs 3) Housework 4) Light-moderate sport/recreation and 5) Vigorous sport/recreation among individuals with disabling conditions. This PASIPD scale has shown adequate internal consistency and the ability to differentiate between those who are active/highly active and those who are not active at all; as well as activity profiles for those in excellent health compared to those with fair/poor health (Washburn et al., 2002).
Quality of Life (QOL)

QOL can be defined as how one’s personal satisfaction and well-being is perceived. It is critical to evaluate an individual’s QOL, especially those living with neurological conditions. According to Aprile et al. (2006), QOL is the most long-term detrimental effect in health and well-being. QOL has been successfully measured using the 36-Short form health survey version 2 (SF-36v2) (Appendix I) (Ware & Sherbourne, 1992). The SF-36v2 has well-established concurrent, predictive, convergent, and discriminate validity; as well as moderate to excellent test-retest reliability (Finch, Brooks, Stratford, & Mayo, 2002). The SF-36v2 health survey reports reliability rates ranging from 0.70 - 0.80.

Summary

This chapter reviewed the literature on the importance of physical activity, it identifies the physical activity levels among individuals with MS, CP and who have recovered from stroke and, barriers and facilitators experienced by those with disability to participating in physical activity. This review of literature also outlined the components of the ICF model as they relate to mobility and those with spasticity resulting from a CNS lesion (Harris et al., 2005; WHO, 2003). In addition, this review outlined the ROM, Gait, mobility, spasticity, QOL and physical activity measures that were used to help characterize ICF domains for this collective population.

There is a paucity literature which has identified a population based on the common experience of spasticity in the lower limb resulting from an CNS lesion which crosses multiple diagnostic categories. No previous research has investigated the interaction between impairments in the body structure and functions, activities and personal or environment barriers to the levels of participation in physical activity and QOL for this population using the ICF model (WHO, 2001). Because individuals with disabilities, including those resulting from CNS lesions experience greater difficulties engaging in physical activity due to the limitations in mobility (Carroll et al., 2006) than those without disability they are more likely to have sedentary lifestyles and negative secondary health outcomes associated with inactivity (Calota & Levin, 2009; Lechner,
Frotzler, & Eser, 2006; Rousseaux et al., 2002; Rimmer, 2005; Skold, Levi, & Seiger, 1999). Social, emotional and physical barriers experienced by those with disability not only limit participation in physical activity, but also influence perceived QOL. Thus understanding the physical activity levels and barriers to participating in physical activity for individuals with disability is more urgent than exploring this for those without disability. Further understanding ways to enhance physical activity levels in those with disabilities will reduce these associated conditions, improve health outcomes and QOL.
Chapter 3: Method

Research Design

This study employed a cross-sectional mixed-method research design. A mixed-methods approach is defined as “[T]he collection and analysis of both quantitative and qualitative data in a single study in which the data are collected concurrently or sequentially, are given a priority, and involves the integration of the data at one or more stages in the process of research” (Creswell, Plano Clark, Gutmann, & Hanson, 2003, p. 212). Mixed-method designs are used to enrich the understanding of individual experiences or issues by an integration of knowledge and conclusions from various methods of data collection. Mixed-method design utilizes the strengths from both qualitative and quantitative research, while providing different perspectives on the same topic (Bazley, 2002). Thus, a mixed-method approach allows for triangulation of data sources and types to take advantage of both the representativeness and generalizability of quantitative findings, and the rich contextual contributions of qualitative data (Punch, 1998). This study is in keeping with current arguments that analyzing both numeric patterns from quantitative data and in-depth details from qualitative data results in a more sophisticated understanding of the research questions (Hanson, Creswell, Plano Clark, Petska & Creswell, 2005; Mertens, 2003).

The participants of the current study are part of a larger experimental study and the current data will serve as baseline data for a subset of the participants in the larger intervention study. Quantitative measures were used to identify the body functions and structures, activities, participation in physical activity and perceived QOL, while qualitative measures were used to understand the barriers and affordances to participation in physical activity. Measures were collected by the University of Victoria (UVic) research team, consisting of two faculty members and five UVic students and; the Vancouver Island Health Authorities (VIHA) clinical team consisting of a psychiatrist, a physiotherapist, and an orthotist.
Participants

Eleven participants were recruited through the VIHA Spasticity Clinic. Clients were referred to the VIHA Spasticity Clinic located at the Queen Alexandra Centre for Children’s Health (QACCH) in Victoria, BC by their physician for treatment for spasticity. The clients were screened by the physiatrist to determine if they met the criteria for inclusion in the study. The inclusion criteria are: a diagnosis of an upper motor neuron (UMN) lesion such as CP, MS or stroke diagnosed a minimum of twelve months prior; experiencing spasticity in the lower extremity muscles; and scheduled to receive therapy that consisted of Botulium Toxin A injections, bracing and physiotherapy for treatment of spasticity to their lower extremity. Participants were not excluded if they are also receiving treatment to upper extremity muscles.

Spasticity clinic clients who met the inclusion criteria for the study, were asked by the Spasticity Clinic administrative assistant (following a script provided, see Appendix J) whether they would be interested in receiving information about the study. With the verbal consent of the potential participant, the administrative assistant provided the UVic research team with the potential participant's telephone number. A UVic research team member contacted the prospective participants by phone to discuss the study (for script see Appendix K). If interested, the participant booked a research appointment at the Spasticity Clinic at which time consent was obtained (Appendix L-N). Two consent forms and one assent form was available: competent adult (Appendix L), non-competent adult (Appendix M), and participant assent (Appendix N). Competence was established by the study physiatrist upon referral to the clinic. Non-competent individuals provided their assent and formal consent was provided by a guardian. This study was approved by the UVic and VIHA Joint Ethics Board.

Characteristics of Participants

A total of eleven individuals (5 women and 6 men) between the ages of 25 - 77 (M = 57) participated in this study. Each participant had a neurological condition resulting from an upper motor neuron lesion and was experiencing spasticity of the lower limb. Out of the eleven participants, six had MS, four experienced a stroke, and one had
CP. Table 1 outlines the characteristics of each participant including age, gender, diagnosis, date of diagnosis, mobility aid and bracing if used and cognition functional status as measured with the MMSE (Folstein & Luria, 1973).
Table 1

<table>
<thead>
<tr>
<th>Part. ID</th>
<th>Age</th>
<th>Gender</th>
<th>Diagnosis</th>
<th>Date of Diagnosis</th>
<th>Mobility Aid</th>
<th>MMSE score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>54</td>
<td>M</td>
<td>Stroke</td>
<td>2008</td>
<td>None</td>
<td>26</td>
</tr>
<tr>
<td>2</td>
<td>68</td>
<td>F</td>
<td>Stroke</td>
<td>1981</td>
<td>Staff</td>
<td>30</td>
</tr>
<tr>
<td>3</td>
<td>77</td>
<td>F</td>
<td>Stroke</td>
<td>2009</td>
<td>Wheelchair</td>
<td>25</td>
</tr>
<tr>
<td>4</td>
<td>25</td>
<td>F</td>
<td>CP</td>
<td>1985 (birth)</td>
<td>Bilateral AFO’s</td>
<td>29</td>
</tr>
<tr>
<td>5</td>
<td>67</td>
<td>M</td>
<td>MS</td>
<td>1982</td>
<td>AFO (left limb)</td>
<td>30</td>
</tr>
<tr>
<td>6</td>
<td>77</td>
<td>F</td>
<td>Stroke</td>
<td>2007</td>
<td>Cane</td>
<td>18</td>
</tr>
<tr>
<td>7</td>
<td>62</td>
<td>M</td>
<td>MS</td>
<td>1981</td>
<td>None</td>
<td>30</td>
</tr>
<tr>
<td>8</td>
<td>39</td>
<td>M</td>
<td>MS</td>
<td>1996</td>
<td>None</td>
<td>30</td>
</tr>
<tr>
<td>9</td>
<td>52</td>
<td>M</td>
<td>MS</td>
<td>2004</td>
<td>None</td>
<td>28</td>
</tr>
<tr>
<td>10</td>
<td>63</td>
<td>F</td>
<td>Stroke</td>
<td>Jan 2008</td>
<td>None</td>
<td>27</td>
</tr>
<tr>
<td>11</td>
<td>48</td>
<td>M</td>
<td>Stroke</td>
<td>Stroke 1 1997,</td>
<td>None</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Stroke 2 2007</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* CP, cerebral palsy; MS, multiple sclerosis

**Procedures**

The participants were assessed at three different times over three months (month 0, 1 and 2). Averages of repeated measurements were used to account for daily variations in the data within a participant. Several measures were used to characterize the domains of human functioning consistent with the ICF. Measures of body functions and structures comprised ankle range of motion, ankle plantar flexor tone and pain. Measures of physical function were walking activities and falls. Participation was characterized through examination of levels, barriers and affordances for physical activity and overall health related QOL. The details of the measures used to evaluate these domains are outlined in the section on Measures.

If spasticity was present in both lower limbs the measures were done bilaterally and averaged for that participant. Measures were implemented according to the schedule outlined in Table 2. At the first visit all measures except the QOL measure were administered. At this first assessment the Folstein’s MMSE was administered. The second assessment took place from one to three weeks after assessment 1. At assessment 2 all the measures were administered, except for the physical activity measures. At assessment 3 all measures were administered. ROM and spasticity measures were
administered by clinical professionals from QACCH Spasticity Clinic and team members from the UVic research team. All other measures were implemented by the UVic research team.

Table 2

**Assessment Timeline for Month 0, 1 and 2**

<table>
<thead>
<tr>
<th>Measures</th>
<th>Time</th>
<th>Assessment 1</th>
<th>Assessment 2</th>
<th>Assessment 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>ROM</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Spasticity measure</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Pain scale</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>TUG</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Walking parameter</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Falls recall</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>PASPID scale</td>
<td>X</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Physical Activity interviews</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>QOL</td>
<td></td>
<td>X</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>MMSE</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

**Measures**

**Body Functions and Structures**

The **Pain Visual Analogue Scale** (VAS) was used in this study to evaluate the participant’s usual and worst level of pain in the past 7 days. Individuals were asked to report any consistent pain in a particular joint/region in their lower body. This joint/region was recorded and the participant was asked to indicate on a 10 cm horizontal line their perceived usual level of pain and worst level of pain during the last week in that joint or region. The level of pain was then quantified by measuring where the mark sat on a continuum from zero (“no pain”) to ten (“worst pain imaginable”). The VAS was administered at each assessment (0, 1, and 2 months). At assessment 1 the participants were asked the following questions:

1) When you’re walking, do you consistently have pain in any particular joint in your lower body? If so, what joint?

2) On a scale of 0 to 10, with 0 being no pain at all and 10 being the worst pain imaginable, how would you rate your USUAL level of pain during the
last week?, and then asked to rate their WORST level of pain on the same continuum.

If individuals indicated more than one location of pain then two VAS assessments were administered. At the assessment 2 and 3 the participants were specifically asked to rate their pain at the joint(s) they had identified at the previous visit. If a new joint was identified at these subsequent assessments then additional VAS assessment was administered. The VAS has high test-retest reliability \((r = .71 - .99)\) (Ahles et al., 1984; Ferraz, et al., 1990; Huskisson, 1974), and moderate validity \((r = .62)\) (Gloth et al., 2001).

**Range of Motion (ROM)** was used to assess mobility at the ankle joint and was measured with a manual goniometer. The angle of the ankle (talocrural) joint was measured during active dorsiflexion with the knee in extension with the patients in supine position. Landmarks for the goniometer arms were the shafts of the fibula and 5th metacarpal and for the axis, the distal end of fibula. This assessment reports high inter-intra reliability \((r = 0.88 - 0.97)\) (Boone et al., 1978; Low, 1978; Rothstein et al., 1983; Salter, 1955).

**Ankle Plantar Flexor Tone Scale (APFTS)** assessed both central and peripheral components of hypertonicity. Peripheral components was measured by passively dorsiflexing the ankle joint and grading the resistance through the range of dorsiflexion using a scale from one to four, one indicating no resistance at the ankle joint and four indicating difficulty with passive movement. Central components of hypertonicity (i.e. spasticity) were measured with a stretch reflex, which involves a quick passive movement into dorsiflexion. Stretch reflex was given a score out of four, one being no twitch at all and four identifying severe clonus lasting >10 seconds. A stopwatch was used to measure the duration of clonus. The clonus beats were also counted and measured accompanied by the quick passive movement into dorsiflexion. All measures were assessed in knee extension. The APFTS reports high Inter-rater reliability \((r = .72 - .94)\). Intrarater reliability also scored high \((r = .63 - .82)\). Number of beats of clonus was measured by counting the beats.
Activities

Functional mobility was assessed using the GAITrite system. It is a pressure sensing mat that gathers data on many spatiotemporal gait parameters; this study analyzed recorded velocity. Participants were asked to walk four passes across the mat at their regular speed with shoes and with the assistive device that they used on a daily basis. Participants were asked to stand approximately one metre away from the start of the mat so when they walked onto the mat they were walking at their full normal speed. Participants walked from one end of the mat to right off the other end of the mat (one pass), they were told to turn around and walk in the opposite direction right off the other end of the mat (two passes). One pass of the mat was approximately eight metres in length. Participants were required to do four passes. One participant was non-ambulatory and did not take part in this assessment. Gait measurements report strong concurrent validity (McDonough et al., 2001) and test retest reliability (ICC scores of 0.96) (van Uden & Besser, 2004).

The Timed Up and Go test (TUG) (Mathias, Nayak, & Isaacs, 1986; Podsiadlo & Richardson, 1991) was used to assess functional ability. Participants were asked to sit in a chair with armrests, with their backs against the seat and their arms on the armrest. On the word “go” stand up from a seated position, walk at their normal pace around a cone placed 3 metres away, walk back to the chair, and sit down. A stopwatch was used to time the participants, starting on the word “go” to when the participant contacted the seat of the chair. Times < 14 seconds has been shown to suggest the participant is at low risk of falling (Shumway-Cook, Brauer, & Woollacott, 2000). This measure reports high intra-rater reliability (r= 0.92 - 0.99) (Podsiadlo, & Richardson, 1991; Rockwood et al., 2000; Schoppen et al., 1999). The TUG has content and concurrent validity (ICC= .92 and .91) and is a valid method for assessing functional mobility (Shumway-Cook et al., 2000).

The fall occurrences were documented by the participants using a custom designed fall recall calendar constructed by the UVic research team. Participants were supplied a calendar at their first appointment and were asked to document any falls, (including a slip or trip in which they lost their balance and landed on the floor or ground or lower level) that they experienced between their first and third assessment. They were
also asked to fill out information surrounding the circumstances of each fall such as time of day, location, and cause. The qualitative details of the falls were discussed and further documented by the UVic research team. If the participant forgot to bring their calendar, researchers questioned the participant on whether they had a fall, documented this and reviewed this fall with the participant at the next appointment with the calendar. Prospective recording method is more reliable than retrospective recall (Hauer et al., 2006; Mackenzie, Byles, & D’Este, 2006) and fall recall assessments have high validity and reliability \( r = 0.79 - 0.95 \) (Rubenstein et al., 1994; Schmid, 1989; Wolf et al., 2003).

**Participation**

**Quantitative:** Participation in physical activity was measured using the PASIPD (Washburn, Zhu, McAuley, Frogley, & Figoni, 2002). The PASIPD is a tool to quantify level of participation in physical activity in those who have disability. It consists of five dimensions of physical activity: 1) home repair and lawn and garden work, 2) housework, 3) vigorous sport and recreation, 4) light and moderate sport and recreation, and 5) occupational and transportation activity. The score for each question was calculated by multiplying the average hours per day for each item by a metabolic equivalent of a task (MET) associated with the intensity of the task. A MET is a physiological term for expressing the amount of energy used during physical activity. One MET is equal to 3.5ml of oxygen per kg of body-weight per minute and is considered the proxy of resting metabolic rate (Kwan, Woo, & Kwok, 2004). Each dimension is represented by a sub-scale score, as well as a total PASIPD score. The minimum and maximum scores for each domain and the total PASIPD are displayed in Table 3. Lower numeric scores reflected the least amount of time and higher scores reflected greater amount of time engaging in physical activity in that domain.
Table 3

*Minimum and Maximum Scores for Physical Activity Survey*

<table>
<thead>
<tr>
<th></th>
<th>Total Score</th>
<th>Home repair &amp; Garden</th>
<th>Housework</th>
<th>Vigorous Sport/Rec</th>
<th>Light-Mod Sport/Rec</th>
<th>Occup. &amp; Transport</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimum</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Maximum</td>
<td>199.5</td>
<td>51.5</td>
<td>30.0</td>
<td>57.9</td>
<td>30.0</td>
<td>30.0</td>
</tr>
</tbody>
</table>

**Qualitative:** Following the administration of the PASIPD, audio-recorded individual semi-structured interviews (Dicicco-Bloom, & Crabtree, 2006) (Appendix O) were conducted to explore barriers and affordances associated with participation in physical activity. Caregivers who attended with some of the participants (i.e. adult, children and community service worker) also contributed some expository comments at the invitation of the participant. Guided by the ICF model (WHO, 2001), informants were prompted to discuss how their condition (i.e. body functions and structures) and contextual factors (personal and environmental) influenced participation in life areas such as work, domestic life, and recreation and leisure. Participants were asked to discuss whether they were as active, less active or more active during the last three months. They were also asked to discuss barriers and affordances for physical activity. Prompts and probes were used to ensure that contextual factors detailed in the ICF were explored. The prompts and probes that were used are identified below:

- **Prompt:** were there things about your health that made it easier or more difficult?
- **Prompt:** did other people influence your level of physical activity?
- **Probe:** How did [Name/role] help/hinder?
- **Prompt:** was there new equipment or new programs?
- **Prompt:** or did you have difficulty getting to activity programs?
- **Probe:** can you tell me about the…new program, difficulty with access, etc.
Health-related Quality of Life (QOL)

Quality of Life (QOL) was measured using the SF-36v2 (Ware & Sherbourne, 1992). The SF-36v2 health survey is a generic measure self-reporting on the following eight health concepts: physical functioning, role limitations due to physical health, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and mental health (Ware & Sherbourne, 1992; Ware, Snow, Kosinski, & Gandek 1993). The 36 questions in the QOL survey make up the total scores for the eight health domains. Refer to Appendix P for which questions in the tool make up these domain scores. Lower numeric scores reflected low QOL as higher scores reflected high QOL. The minimum and maximum scores for each health domain are in Table 4.

Table 4
The Minimum and Maximum Scores for each Health-related QOL Domain

<table>
<thead>
<tr>
<th></th>
<th>Physical Functioning</th>
<th>Role Physical</th>
<th>Bodily Pain</th>
<th>General Health</th>
<th>Vitality</th>
<th>Social Functioning</th>
<th>Role Emotional</th>
<th>Mental Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimum</td>
<td>10</td>
<td>4</td>
<td>2</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Maximum</td>
<td>30</td>
<td>20</td>
<td>12</td>
<td>25</td>
<td>20</td>
<td>10</td>
<td>15</td>
<td>25</td>
</tr>
</tbody>
</table>

Scoring of the SF-36v2 can produce both raw scores and norm-based scores. In norm-based scoring, each scale is scored to have the same average (50) and the same standard deviation (10), meaning each point equals one-tenth of a standard deviation. Individual respondent’s scores below 45, or a group mean scores below 47, indicate a health status that is below the average range. Norm-based scoring which employs a linear T-score transformation with mean = 50 and standard deviation = 10, makes it possible to meaningfully compare scores for the eight-scale profile and the physical and mental summary measures (Saris-Baglama et al., 2007). SF-36v2 scoring software also yields less biased estimates of missing responses and makes it possible to estimate scores for more respondents with incomplete data (Kosinski, Bayliss, Bjorner, & Ware, 2000). Two summary measures of the SF-36v2 are the Physical Component Summary (PCS) and Mental Component Summary (MCS), which are constructed from the eight sub-scales.
Though all the sub-scales contribute to the scoring of both the PCS and MCS measures, Physical functioning, Role physical, Bodily Pain, General Health Scales contributing primarily to the PCS while Vitality, Social functioning, Role Emotional and Mental Health contribute primarily to the MCS.

**Cognitive Assessment**

Mini Mental State Evaluation (MMSE) is a cognitive exam with questions designed to evaluate an individual’s orientation, registration, recall, attention and calculation, language, following directions, perception and judgment. This assessment was administered to establish a cognitive functional level for each participant to be used solely as a descriptor of the sample. The scale ranges from 0-30; 26-30 could be normal cognition; 20-25 mild cognitive impairment; 10-19 moderate cognitive impairment; 0-9 severe cognitive impairment. Individuals MMSE scores are displayed in Table 1. A review on the MMSE found high test-retest reliabilities ($r= .80 -.95$) (Anthony et al., 1982; Dick et al., 1984; Tombaugh & McIntyre, 1992; Molley et al. 1991).

**Data Treatment and Analyses**

**Quantitative.** Data gathered from all measures at the three assessments were averaged. Descriptive statistics (mean, standard deviation and range) were used to summarize the measures of body functions and structures, activities, participation in physical activity and perceived health-related QOL. Pearson’s correlations were used to determine relationships between body functions and structures, activities, participation in physical activity, and perceived health-related QOL. Raw scores from each QOL sub-scale were used for correlations analyses, but norm-based scores are used for interpretation. A critical $r$ value of $.576$ for a two-tailed test at $p < 0.05$ was used based on ten degrees of freedom (n-1) to determine significant correlations (Howell, 2004). Difference in TUG scores between fallers and non-fallers was examined using an independent t-test and effect size was calculated using the following formula ($M2 -M1 / \text{pooled SD}$) (Cohen, 1992).
**Qualitative Data Treatment.** The interviews were recorded using a digital audio recorder and transcribed verbatim by the principal investigator. The transcripts were read several times by both the principal investigator and one supervisor (VT) to gain a sense of the whole and to become immersed in the detail. Using an orientational approach (Patton, 1990) the transcripts were coded using a deductive a priori template of codes approach (Crabtree & Miller, 1999). The codebook template was based on the five Environmental Factors sub-sections of the ICF (World Health Organization, 2001); specifically: products and technology; natural and human made environment; support and relationships; attitudes; and services, systems and polices. In addition personal factors and the influence of the participant’s health on participation were coded openly. The framework for interpreting the codes consisted of consideration of the actual words and their meaning, the context, the frequency and extensiveness of comments, the intensity, internal consistency, and specificity of responses, and larger trends (or big ideas) within these data.
Chapter 4: Results

Body Functions and Structures

Average scores across participants for the body functions and structures measures (range of motion, muscle tone, clonus and pain) are displayed in Table 5. The range of dorsiflexion motion with the knee extended was 35°PF to 5.0°DF. That is, on average the participants were not able to actively move the ankle joint to neutral with the knee extended, but rather the ankle remained on average plantar flexed to 9.98°. On average mild to moderate muscle tone with knee extension was found using the APFTS for middle range resistance (M= 1.56, SD= 0.49, range 1-3). As seen in Table 5, participants experienced a mean of 2.88 (SD= 5.00) clonus beats with a range of 0 to 17.5. The stretch reflex scores show that participants on average experienced mild clonus persisting < 3 seconds (M= 1.64, SD = 1.13, range 0-4). Range of Motion and spasticity measurements were taken bilaterally for Participants # 4, 5, and 8 who had bilateral limb involvement. On average participants reported a mean score of 1.74/10 (SD =2.78) for worst level of pain with a range of 0 to 9.39 and on average a usual level of pain of 1.10/10 (SD = 1.82, range 0-5.40). Six participants reported no pain, while five participants reported pain including Participant #11 who reported two locations of pain. Individual body functions and structures scores for each measure for each participant can be found in Appendix Q.

Table 5

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean</th>
<th>SD</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active ROM Knee Extended (°)</td>
<td>9.98 PF</td>
<td>10.45</td>
<td>35.00PF</td>
<td>5.00DF</td>
</tr>
<tr>
<td>PFTS Knee Extended (°)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stretch Reflex</td>
<td>1.64</td>
<td>1.13</td>
<td>0.00</td>
<td>4.00</td>
</tr>
<tr>
<td>Middle Range Resistance</td>
<td>1.56</td>
<td>0.49</td>
<td>1.00</td>
<td>3.00</td>
</tr>
<tr>
<td>Clonus Knee Extended (# of beats)</td>
<td>2.88</td>
<td>5.00</td>
<td>0.00</td>
<td>17.50</td>
</tr>
<tr>
<td>Visual Analogue Pain Scale (1 out 10)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Usual Past Week</td>
<td>1.10</td>
<td>1.82</td>
<td>0.00</td>
<td>5.40</td>
</tr>
<tr>
<td>Worst Past week</td>
<td>1.74</td>
<td>2.78</td>
<td>0.00</td>
<td>9.39</td>
</tr>
</tbody>
</table>
Activities of Functional Mobility

Moderately high mean TUG scores across participants, described in Table 6, indicate a high risk of falling among participants. Participant #3 uses a wheelchair for mobility and is non-ambulatory; therefore she did not complete the TUG and Gaitrite assessments. Out of ten participants who completed the TUG assessment, five scored >14s and four of them experienced a fall. These were participants #1, #2, #5, #6, and #10. Fall occurrences were low among all participants (M = .91, SD = 1.04, range=0.00-3.00). Six participants experienced falls over a 2 month period: Participant #3, #2 and #6 fell once, Participant #4 and #10 fell twice, Participant #5 fell three times. Injuries among the participants were as follows: Participant #2 fell and was injured, Participant #3 fell once and experienced a non-displaced subcapital left hip fracture, Participant #5 experienced an abrasion on the knee at the first and on the elbow at the second fall and no injury on the third fall; Participant #10 experienced minor bruising on both falls. Participant #6 and #4 did not sustain any injuries. Participant #3 fell, however, was not included in the mean TUG scores among the fallers because this participant was not ambulatory and did not complete the TUG assessment. An independent t-test revealed there was no significant difference in TUG scores between fallers (M = 25.16, SD = 14.10, range= 13.70-43.41) and non-fallers (M = 11.25, SD = 3.46, range= 7.90- 17.16), p = .09; although the effect size was large d = 1.95. Gait velocity was measured in centimetres/second using the GAITrite mat system (M = 74.94m/s, SD = 35.52, range= 21.25-130.50). Individual functional mobility assessment scores for each participant can be found in Appendix R.

Table 6

Functional Mobility Scores (Activities)

<table>
<thead>
<tr>
<th>Measure</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>Range Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>TUG</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Combined (sec)</td>
<td>10</td>
<td>18.18</td>
<td>12.16</td>
<td>7.90</td>
<td>43.41</td>
</tr>
<tr>
<td>TUG for those with falls (sec)</td>
<td>5</td>
<td>25.16</td>
<td>14.10</td>
<td>13.70</td>
<td>43.41</td>
</tr>
<tr>
<td>TUG for those with no falls (sec)</td>
<td>5</td>
<td>11.25</td>
<td>3.46</td>
<td>7.90</td>
<td>17.16</td>
</tr>
<tr>
<td>Fall Occurrences (number)</td>
<td>11</td>
<td>0.91</td>
<td>1.04</td>
<td>0.00</td>
<td>3.00</td>
</tr>
<tr>
<td>Gait Velocity(cm/sec)</td>
<td>10</td>
<td>74.94</td>
<td>35.52</td>
<td>21.25</td>
<td>130.50</td>
</tr>
</tbody>
</table>
Physical Activity

Survey: Overall levels of physical activity as well as sub-scale dimensions of physical activity are presented in Table 7. These data demonstrate considerable between-individual variability. Table 7 illustrates that the highest total PASIPD (Participant #2) was 41.4 MET hr/day and the average for all participants was 9.5 MET hr/day. These scores are well below maximum possible scores (see Table 3).

Table 7

| Individual Averages for Physical Activity and Sedentary Behaviour |
|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
|                 | Total Score     | Home repair & Garden | Housework | Vigorous Sport/Rec | Light-Mod Sport/Rec | Occup. & Transport |
| 1               | 1.2             | 0.0               | 0.6       | 0.0               | 0.3               | 0.3               |
| 2               | 41.4            | 11.8              | 12.9      | 7.1               | 3.9               | 5.8               |
| 3               | 2.4             | 0.0               | 0.2       | 0.9               | 0.6               | 0.7               |
| 4               | 6.2             | 0.0               | 0.3       | 1.3               | 1.8               | 2.8               |
| 5               | 4.6             | 0.0               | 0.0       | 0.0               | 0.0               | 4.6               |
| 6               | 11.2            | 0.0               | 0.4       | 0.3               | 3.3               | 7.2               |
| 7               | 9.6             | 0.9               | 2.4       | 0.0               | 0.8               | 5.6               |
| 8               | 4.2             | 0.0               | 2.9       | 0.0               | 0.0               | 1.3               |
| 9               | 7.1             | 0.9               | 5.0       | 0.0               | 1.0               | 0.3               |
| 10              | 10.1            | 0.4               | 3.5       | 2.5               | 3.1               | 0.5               |
| 11              | 6.2             | 0.0               | 0.2       | 1.4               | 3.7               | 0.9               |

All Participants
Mean 9.5 1.3 2.6 1.2 1.7 2.7
SD 11.0 3.5 3.8 2.1 1.5 2.6

Note. Scores for Participants #1 and #9 is based on 1 assessment

Semi-structured interviews: Three major themes emerged from the analysis of interview transcripts, these were: “The weather and a fear of falling”; “Getting back to it”, and “Helpful, but not always accessible”. A physical activity interview transcript is displayed in Appendix S.
Theme 1: The weather and a fear of falling

Like others who do not experience spasticity, the weather was often a barrier to participation in physical activity. Most participants mentioned doing less activity when the weather was poor as well as looking forward to doing more when the weather improved. For example, Participant #11 described how the weather affected his bike riding:

….sometimes the weather affects my participation in physical activity because it was snowing up at my mom’s house so I couldn’t do any bike riding (...) if a car comes along you have to jump off into the snow pile.

Well I usually walk more when the weather is better. But the rain influences me to stay in. (Participant #7)

Weather related changes in behaviour also included choice of mode of transportation. Participants expressed reluctance to walk in inclement weather, as Participant #4 said, “if it is raining I take the bus.”

Interactions between dimensions of disability were also evident when participants described their concerns about the weather. Participants consistently mentioned that their impairment (in body functions and structures) limited participation in poor weather. A fear of falling was often expressed.

The weather can really be a decision maker or breaker...my balance, because even though I wear bilateral braces and good snow shoes...a good day is where it is sunny and [the] pavement is dry and not covered with ice or rain (Participant #4)

...we stay home when the weather is poor because she feels unsafe...this time of the year it’s her confidence ... she feels that every crack in the sidewalk is a barrier for her. (Son of Participant #6)

...it depends on weather, I won’t go out if it’s raining because I can’t hold my umbrella and cane at the same time and it’s more dangerous.
I’d take the car if it’s raining and if it’s sunny I’d walk. (Participant #8)

If it is too slippery out I don’t want to go out and I haven’t [fallen] in a while since last time. I don’t fall often, but I don’t want to fall. (Participant #10)

**Theme 2: A desire to get back to it**

There was a strong sense of participation restrictions, with many individuals explaining that their life roles were more limited now due to their health condition. Participation restrictions were noted in the life roles of work, recreation and leisure, self-care, and domestic life. Limitations in body functions and structures were creating additional daily challenges and risks. For example, Participant #8 said that his muscle weakness and imbalances as well as reduced mobility were restricting his life roles, including self-care.

…Well because of the MS….. Well just walking in general like going to the bathroom, being in the shower, I have fallen in the shower, getting in and out of the shower, falling in the tub, falling getting off the toilet, getting on the toilet, falling on the floor, tripped on the carpet, going to the couch. This and that, I have had lots of falls.

Another body function and structure identified was pain. Pain restricted mobility and limited participation in recreation and leisure activities as well as housework. Participants said they accomplished less; and did not attempt things, or stopped participating in activities due to pain.

None of the participants were currently in paid employment, and for some this was directly related to their health condition. Participant #11, who used to wash buses for a living, explained, “It’s because of my foot that I cannot work right now. If I can get the treatment and get my foot working properly, I will probably start working again”.
Restrictions in participant’s abilities to perform household tasks were common and also very concerning and upsetting for some. Participants’ concerns were mainly related to the burden they felt they were placing on others. Those who described housework activities noted that they still did what they could but were limited to minor duties. As Participant #8 said “…yes I clean the house, I still do that. My girlfriend does the heavy stuff but I do the light housework for sure. Dishes, sweep the floors”. Participant #3 cried when she spoke about how she used to cook and clean at home but can’t now. She expressed frustration with her body and feelings of guilt about not being able to do the housekeeping for her family.

The majority of participants said they enjoyed being active; and many recounted that that had been more active in the past. As Participant #3 explained “I have always been an active person that’s why it is so hard to sit in a chair all day and I would really like to get up and go and do something… now I never think about going [swimming] because I am in a wheelchair.” Participants also expressed frustrations about how their health condition impaired their current participation in recreational activities.

My foot is a huge barrier to my participation in physical activity. I like to go on longer bike rides. It doesn’t really slow me down there, but walking! Yeah my foot doesn’t allow me to walk for very long because my foot starts to hurt. (Participant #11)

The majority of the participants said they enjoyed being active, but were limited in the types and kinds of activities due to their impairments.

Despite the activity limitations and participation restrictions related during the interviews, participants expressed a desire to participate more fully. With the exception of Participant #4 who had always lived with cerebral palsy, participants expressed a desire to regain functioning and to get back to some of the things they did before their injury. As Participant #1 said, “[I want] to be able to walk normally”. Participants were doing many things to improve their functioning and participation. Home- and community-based physiotherapy/rehabilitation programs were evident. For example, Participant #2 said, “I do stretches and when I was stretching I was lying down stretching my ham[string]
muscle and I couldn’t do it at first but I can do it every night”. Four of the participants indicated that involvement in rehabilitation and community programs helped them reduce their impairment, increase activity and participation, and enhance their health. For example Participant #10 said,

Well, my physiotherapist set up a program for me to do in the pool that includes all the muscles groups and range of motions. She also makes me go to a gym. She gave me a bit of a gym program. I do this machine thing called the new step but I go way beyond that now. I remember when I could only do the first few levels.

Despite being early in their treatment, the VIHA spasticity clinic program and this study also appeared to be helpful and motivating. Participant #8 said he does stairs at home “Because I am doing this study and I want to get better. I want to get my muscles working again”. Participant #2’s husband felt very positive about his wife’s experiences with the VIHA spasticity clinic program.

…..Well we really are enjoying this program. We leave feeling really happy. Because Jamie comes up with new exercises and Dr. Quartley gives new suggestions and the brace today was new and it really gives me hope that I am going to be okay.

Non-clinical community-based programs were also mentioned as a source of enhanced participation in life roles. Participant #6’s son said that if it were not for the programs and structured activities his mom wouldn’t be as active or have the incentive to get back participating. He spoke of the importance of having a program specifically for individuals who had experienced stroke where “everyone is in the same boat”. He felt the vicarious experience of seeing others succeeding who had a similar condition was motivating for his mother.

The social support of friends, family and support workers also facilitated efforts to increase physical activity and functioning. For example, Participant #10 says a little “come on, you can do it” from their spouse encourages their participation. Other participants agreed that their support networks encouraged participation in physical
activity. For example, Participant #11 said his son “… wanted to take pictures [at top of Mount Doug] and I told my son ‘do you realize we have to walk to the top?’ and he said, ‘Yeah.’ So I said. ‘Okay let’s go to the top’.

The participants identified that they participated significantly less due to barriers associated with their health condition. These participants identified barriers of body functions and structures that caused activity limitations and participation restrictions. The interaction of the contextual factors identified in these interviews facilitated and/or hindered participation. However, participants outlined the importance of getting back to it and trying to regain what they had lost due to their health condition. Factors that facilitated participation was the use of services and the encouragement of key individuals in their lives.

**Theme 3: Helpful, but not always accessible**

Services and systems were a feature of the previous theme; however participants also indicated that access to systems and services were somewhat problematic. Participants found that community programs encouraged their level of participation, providing both skill development and access to opportunities. Programs such as the Brain Injury Program at The Cridge Centre for the Family and Transitions Outreach Program for adults with a developmental disability were noted. These programs provide support for activities of daily living (e.g. grocery shopping), as well as educational, recreational, employment, and social opportunities. When speaking of the Transitions program, Participant #4 explained:

> They give their clients the skills necessary to go out and find work to be safe on the streets and to learn how to take the bus. Generally just gives them the skills so that at some point or another they can go out to a job and can get home safely. They can go to the grocery store and pick up groceries and get home the same way.

Although, these programs facilitated participation in physical activity and life roles more generally, there were access barriers that made participating more difficult. The barriers outlined were: program cutbacks, transportation issues, and program cost.
Participant #10 who belonged to the Cridge program, said there had been cutbacks on the frequency of care provided by the social workers. “We meet twice a week now, Tuesdays and Thursdays. I had somebody before coming in five times a week but they cut down on my hours”. This participant said she stayed home more now due to the cutbacks and participated significantly less.

Transportation, in general and to programs specifically, was also an issue. Despite having been taught how to use the Victoria Regional Transit handyDART bus system at the Cridge, Participant #10 doesn’t use it because it is difficult to get bookings and wait times are long. When asked if she used the handyDART she said “no no …hahaha, because you have to order it!” She found it more convenient to get a ride with her community support worker; otherwise she would just stay home. Participant #6’s son also expressed concerns with transportation. He explained that their family could not always drive their mother to the day programs because everyone worked and taking public transportation is too difficult because of her impaired speech and gait.

Cost of services was also a barrier to participation. Participant #4 wanted to take dance lessons, Participant #8 wanted to swim more, and Participant #10 wanted to join a seniors program at a local gym; but each person found the cost prohibitive. As Participant #10 said ironically:

Participant #10: The Juan de Fuca centre offers an incredible list of activities, like crafts, sign language classes, learning Spanish.

Interviewer: So are you thinking about joining?

Participant #10: Yeah [sarcastically] … it costs $90!

Subsidies for individuals living with a health-condition were noted. Participant #8 was waiting for his income to be re-assessed now that he earned less, so that he would become eligible for a low income recreation subsidy at his local recreation centre; and Participant #10 found the Leisure Assistant Pass useful.
Oh yes [cost is a barrier] but I bought various things like two passes. Another thing that [my husband] and I did is get a yearly pass to IMAX and I get in for free because I have already paid for it and I have an assistant pass that [my husband] can use. Bless that assistant’s pass.

In the context of the ICF model, environmental factors such as, services and systems were a feature of participation in physical activity. Individuals outlined their positive experiences with participating in these events. However, cutbacks, transportation difficulties, and cost were limiting participation.

**Health-Related Quality of Life (QOL)***

Tables 8a and 8b illustrate the participants’ raw- and norm-based scores for the eight health domains of the QOL SF-36v2 health survey. Self-reported scores seen in Table 8a and 8b indicate the individual scores as well as means and SD across participants for each health domain. The possible minimum and maximum scores for each health domain can be viewed in Table 4. The QOL assessment was not gathered from Participant #9.
### Table 8a

**Individual Raw Scores of Health-Related Domains of the Quality of Life Survey**

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<th>Bodily Pain</th>
<th>General Health</th>
<th>Vitality</th>
<th>Social Functioning</th>
<th>Role Emotional</th>
<th>Mental Health</th>
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**All Participants**

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<th>Vitality</th>
<th>Social Functioning</th>
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<th>Mental Health</th>
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Table 8b

*Individual Norm-based Scores of Health-Related Domains of the Quality of Life Survey*

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<th>Vitality</th>
<th>Social Functioning</th>
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Relationships between Physical Activity and Quality of Life Measures

As seen in Table 9 a correlation analysis was conducted on all dimensions of the physical activity and QOL measures. Correlation coefficients is significant at p<0.05 (r>.576) and are shown in boldface in Table 9 and 10. There was a moderate significant relationship between Vitality and the Total PASIPD (r = .67); Home Repair (r = .67); and Housework (r = .62). A moderate relationship was also found between Mental health Total PASIPD (r = .59); Home Repair (r = .60); and housework (r = .64). Strong significant correlations were found between Bodily pain and Social functioning (r = .91).
### Table 9

**Correlations between the Physical Activity and QOL Measures**

<table>
<thead>
<tr>
<th></th>
<th>Total PA</th>
<th>Home Repair</th>
<th>Housework</th>
<th>Vig Sport /Rec</th>
<th>Light-Mod Sport/Rec</th>
<th>Occup /Transp</th>
<th>Physical functioning</th>
<th>Role Physical</th>
<th>Bodily Pain</th>
<th>General Health</th>
<th>Vitality</th>
<th>Social Functioning</th>
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<th>Mental Health</th>
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<td>0.59</td>
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</table>

*Note.* *r > .576 (p < .05),* boldface indicates significant correlations.
Relationships between Body Functions and Structures, Activities, QOL and Physical Activity

As seen in Table 10 a moderate significant negative correlation was observed between Occupation/Transport and Active dorsiflexion knee extended (r = .58) and, Knee extended stretch reflex and Light to Moderate Sport and Recreation (r = .69). TUG was positively correlated with Total Physical Activity (r= 0.63) and with Occupation/Transport (0.69). A high inverse relationship was found between QOL Bodily pain and Usual pain (r = -.74) as well as, Worst pain (r = -.70). A moderate inverse relationship was found between Social functioning and Usual pain (r = -.64) and Worst pain (r = -.57). A moderate inverse relationship was found between Knee extended stretch reflex and general health (r = -.58) and a positive relationship between Knee extended stretch reflex and Role emotional (r= .69).

Table 10

<table>
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<th></th>
<th>ADKE</th>
<th>Gait Velocity</th>
<th>Falls</th>
<th>Usual pain</th>
<th>Worst Pain</th>
<th>TUG</th>
<th>Clonus Knee Extended</th>
<th>Knee Extended Stretch Reflex</th>
<th>Middle Range Resistance</th>
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<td>-0.21</td>
<td>0.19</td>
<td>-0.09</td>
</tr>
<tr>
<td>Role Emotional</td>
<td>0.13</td>
<td>0.02</td>
<td>0.05</td>
<td>-0.17</td>
<td>-0.34</td>
<td>-0.14</td>
<td>0.42</td>
<td><strong>0.69</strong></td>
<td>0.05</td>
</tr>
<tr>
<td>Mental Health</td>
<td>0.02</td>
<td>-0.27</td>
<td>-0.35</td>
<td>-0.11</td>
<td>-0.08</td>
<td>0.36</td>
<td>-0.25</td>
<td>-0.26</td>
<td>0.04</td>
</tr>
</tbody>
</table>

Note: * r > .576 (p < .05); bold identifies significant differences; ADKE, Active Dorsiflexion Knee Extended
Chapter 5: Discussion

The aim of the study was to better understand the influence of body structures and functions, activities and contextual factors on participation in physical activity in those with a CNS lesions resulting in lower limb spasticity. An additional aim was to better understand the interaction between participation in physical activity and QOL.

This was done through a unique approach of identifying a population based on the common experience of spasticity in the lower limb resulting from an CNS lesion across multiple diagnostic categories and using the International Classification of Functioning, Disability and Health model (ICF) (WHO, 2001) as framework to characterize this population and explore interactions among the domains.

Body Functions and Structures

The current results show that each member of this cohort experienced significant physical impairments for multiple body functions and structures. For example, ROM among this population was limited such that eight out of eleven participants were not able to actively dorsiflex enough to have adequate toe clearance in the swing phase of gait which impacted functional walking abilities. While typical ankle ROM allows for 20°DF to 50°PF, this cohort on average was not able to dorsiflex past 9.98°PF (SD 10.45°). Previous work has similarly identified limited ankle ROM as a common impairment in those with UMN lesions (Carroll et al., 2006; Van der Salm, Veltink, Hermens, IJzerman, & Nen, 2005). Further, this cohort experienced increased muscle tone in the ankle plantar flexors as indicated by mild to moderate resistance for middle range. Only a mild degree of spasticity was observed with an average of three beats of clonus in response to a quick stretch. Increased ankle plantar flexor muscle tone is a known common impairment associated with UMN lesions (Adams & Hicks, 2005; Takeuch, 2009). On average pain was reported as not being a significant factor among this cohort (usual pain, M= 1.10, SD= 1.81; worst pain, M= 1.74, SD= 2.78) with six participants reporting no pain. However, five participants reported experiencing significant pain in a lower limb joint.
Activities of Functional Mobility

On average the cohort presented with mild to moderate impairments in their mobility as measured by TUG, Gaitrite and falls. The walking velocity scores among this cohort (M= 74.94 cm/s, SD= 35.52) were slower than a typical older adult cohort with no neurological conditions (122.67 cm/s) (Escalante, Lichtenstein, & Hazuda, 2001). Slower velocity is typically related to physical impairments (eg: fatigue, balance, reduced ROM) associated with CNS lesions (Crenshaw, Royer, Richards, & Hudson, 2006). TUG scores were on average higher among study participants (M = 18.18 sec, SD= 12.17) than for older adults with no neurological conditions (M 10.04 sec, SD= 2.15; age 65-69 years) (Thompson & Medley, 1995). This average time of 18.8 seconds indicates a high risk for falls, given that > 14 seconds is associated with increased fall risk (Shumway-Cook et al. 2000). In fact four participants out of five who completed the TUG reported falling over the 2 month period scored ≥ 14 seconds. On average the risk of falling among this cohort was .91 falls/person. This is significant given the negative health outcomes that can result from a fall as experienced by Participant #3 who experienced a fractured hip. Though no significant difference was found in TUG scores between fallers and non-fallers in this study, the effect size was large (d = 1.95); with an increase sample size it is predicted that a significant difference would emerge. Previous research found that falls are common among stroke survivors (Esquenazi, 1995), specifically for participants with spasticity.

Participation in Physical Activity

The findings from both the survey and semi-structured interviews suggest that participation in physical activity is low; and lower than participants desire. Table 7 illustrates that Housework and Occupational and Transportation activities were the most common sources of physical activity. All of the participants did a little walking or wheeling outside the home that was not for exercise; but few participants engaged in work- or volunteer-related physical activity. The participants indicated that their health condition limited their ability to work; although three participants did accumulate some work-related physical activity. While Participant #5 worked 24 hours per week as a University professor, the MET hr/day was still quite low because the intensity of this activity was light. The two other participants worked less than four hours per week. One
of those participants, Participant #4, was engaging in a work training program for persons with developmental disabilities. Unlike the other participants who had generally stopped working because of their acquired health condition, Participant #4 had lived with cerebral palsy all of her life and was learning skills to obtain her first job. She indicated that she was quite motivated by the fact that she was paid to clean at a childcare centre. Both the mean and individual scores for Occupational and Transportation-related physical activity in Table 7 are considerably lower (i.e. 2.7 MET hr/day) than the mean of 11.9 MET hr/day reported by Washburn et al. (2002) among 260 persons with spinal cord and disabling locomotor conditions. The very low levels of walking for transportation in this particular group may reflect the impaired mobility described in the previous section as well as the expressed concerns about falling. This is consistent with previous research that demonstrates that the weather (Rimmer et al., 2004; van der Ploeg et al., 2004) and poor balance (Clarke et al., 2008) are barriers to participation in physical activity for persons with disabling conditions.

Although the volume and intensity of housework-related physical activity was generally low; all but one participant engaged in housework. Indeed many participants expressed a desire to do more. Participants indicated that family members were often filling this role; performing many of the tasks they used to do, including much of the heavier housework. This produced feelings of guilt and frustration for several participants. These findings are consistent with previous research which shows that household activities, such as, cooking, cleaning, preparing meals, shopping and doing laundry are difficult among individuals with disabilities (Adams & Hicks, 2005, Welmer, Arbin, Holmqvist, & Sommerfeld, 2006; Bhakta et al., 1996; Mayo, Wood-Dauphinee, Cote, Durcan, Carlton, 2002) and the findings of Mayo et al. (2002) who reported that individuals recovering from stroke have many limitations with household activities. When the findings in this study are specifically compared with individuals with disabling locomotor conditions in the Washburn et al. (2002) study, levels of housework-related physical activity are comparable (2.6 MET hr/day and 2.5 MET hr/day, respectively). Similarly, participation in home repair and lawn and garden work in this sample was very low and comparable with the Washburn et al. sample (1.3 and 1.5 MET hr/d, respectively). There was one notable exception to this finding. Participant #2 engaged in
considerable housework and home repairs despite experiencing spasticity and decreased range of motion (see Appendix Q), a fall (see Appendix R), and limitations in mobility characterized by very slow TUG scores and walking speed (see Appendix R). At the time of this study, Participant #2 and her husband were actively renovating their house; which was a major source of physical activity in the housework and home repair dimensions of the PASIPD.

The final domain of the PASIPD is participation in sport and recreation. This domain consists of two dimensions 1) participation in strenuous activities such as jogging, walking with crutches, and weight training, and 2) participation in moderate and light sport and recreation like golf with a cart or therapeutic exercises. The mean scores for these dimensions are again very low and consistent with scores provided by Washburn et al. (2002) for individuals with locomotor-related conditions. These scores are also reflective of participation in leisure-related activity by persons with chronic conditions (Sawatzky et al., 2007). Sawatzky and colleagues reported that individuals with chronic disabling conditions participate in very little leisure-related activity (~ 1,000 kcal/week) as a result of their health condition. These scores are perhaps indicative of what most participants described in Theme 2; lower participation since their injury. However, participants were engaging in both therapeutic and community-based exercise. Individual activities such as bike riding, swimming and weight training were mentioned by participants. Team sports were not a feature of participation at all. There was also a strong desire to do more; but cost, a lack of transportation, and cut-backs to services were reported to be restricting participation. Both cost and transportation barriers have been previously reported as barriers in the literature (Rimmer et al., 2004; Rimmer & Hedman, 1998; van der Ploeg, et al., 2004); as has access to fitness and recreation centres and programs (Ellis, Kosma, Cardinal, Bauer, & McCubbin, 2007; Rimmer et al.). Ellis and colleagues found that individuals with physically disabling conditions believed that increased programming and support would facilitate their enhanced participation. However, fiscal cut-backs resulting in reduced program days and level of community service worker (caregiver) support within this context has received little attention in the literature
Health-related Quality of Life

Norm-based QOL scores results were interpreted in relation to norm-based scores derived from the general United States population where group scores below 47/100 indicate a below average health status and individual scores below 45/100 indicate below average health status. In the present study the physical component summary (PCS) scores were lower than average norms (M=38.12, SD=7.53), while the mental components summary (MCS) scores were on par with average ranges (M=50.61, SD=10.02).

The overall PCS score is reflected in the physical health sub-scores. Participants, on average, rated their Physical Functioning, which included their ability to lift, carry, climb, bend, stoop, kneel and walk a moderate distance, well below average (M= 32.75, SD=9.0). Further, on average participants reported that their ability to engage in physical activity (Role Physical) was well below average (M=34.22, SD 10.77). The current findings are supported by previous reports which indicate that those with physical impairments find it challenging to carry out ADLs and participate in physical activity (Carroll et al. 2006). On average participants reported Bodily Pain that was within average range (M= 47.18, SD=11,00). This cohort may have reported little pain because they had limited spasticity and high levels of pain are often related to high degrees of spasticity in those with UMN lesions (Sawtzky et al. 2007). Participants’ rated their General Health in the middle of the normal range (M=50.89, SD 7.3) generally saying their overall health was ‘good to very good’ and ‘were a little healthier or the same’ as others. Therefore this cohort reported that their physical impairments limited their physical activity, but they did not see themselves as unhealthy or unwell compared to others. The physical health QOL sub-scores corroborate the qualitative and quantitative physical activity findings of reduced ability to participate in physical activity.

The overall MCS score (M=50.61, SD=10.02) was slightly higher than the trend reflected in the mental health sub-scores. On average participants’ Vitality scores were within the normal range (M=47.56, SD 8.48). This is interesting given that that many participants reported they felt energy “some of the time” and felt tired, worn out, or lacked energy “some of the time”. This suggests the general population had similar responses. Participants reported that physical health interfered ‘a little or slightly’ with social engagement as seen with on overall Social Functioning score that was slightly
below the average range (M=45.92, SD=7.91). Gordon et al. (2004) similarly reported that post stroke individuals found that their residual physical deficits contributed to a decline in social interaction and withdrawal. On average participants reported that their emotional health interfered with activities “a little or some of the time” with a mean Role Emotional score slightly below average (M=45.20, SD 11.43). This result is consistent with previous research which found that individuals with disabling conditions had difficulties with ADL due to emotional health (Sawatzky et al., 2007). The Average Mental Health score (M=46.21, SD 10.00) was minimally below the average range for the general population. This score and other mental health sub-scores suggest that this cohort has a more positive outlook on their mental health than previously reported. Those living with disabling conditions often exhibit feelings of depression, anxiety and fear (Sawatzky et al., 2007; Rimmer, 2005). This discrepancy may be due to the support networks reported by participants in the study. Many reported receiving assistance from spouses, partners, children, grandchildren, friends and support workers who created positive surroundings engendering positive emotional and mental health (Rimmer et al., 2004).

**Relationships between Domains of the ICF**

The ICF is a framework around which changes in body function and structures and activities resulting from a health condition associated with UMN lesions could not only be characterized, but an understanding has been gained on how the relationship between these components and the contextual factors, both personal and environmental, have ultimately influenced participation in life roles. This understanding of participation, though physical in nature, spans across life roles including areas of work and employment, recreation and leisure, domestic life and selfcare.

The results of this study clearly show that this group of participants experiences impairments in their body functions and structures. On the whole these individuals have decreased ankle ROM, spasticity, some have pain, and they walk slowly with decreased mobility and experience falls and increased risk for falls. The volume and intensity of physical activity for these individuals is extremely low; hampered by physical impairments, fear of falling, cost of activities, poor weather, a lack of transportation, and
cut backs to services as reported in the semi-structured interviews. The results distinctly align with the ICF model. The contextual environmental factors (e.g., weather) and contextual personal factors (e.g. motivation or fear of falling) influence and shape the participation in physical activity. The quantitative relationships between the domains of the ICF are less obvious. Consistent with the qualitative findings, measures of spasticity (e.g. Knee Extended Stretch Reflex) were inversely correlated with Light to Moderate Sport and Recreation and General Health. There was a negative relationship between pain measures (elicited via the SF-36v2 and the VAS) and Social Functioning (SF-36v2). Pain was also mentioned as a limiting factor in the qualitative interviews by those who experienced pain, but was not associated with PASIPD measured physical activity. The quantitative relationship may be unclear due the fact that only a few participants experienced pain.

One surprising relationship was revealed between TUG scores and overall physical activity and occupational and transport related physical activity. Higher TUG scores (less mobile) were associated with higher levels of physical activity. After detailed examination of the individual data, it was revealed that the two, slowest TUG scores were exhibited by individuals who were motivated to be physically active despite their poor mobility. Two spurious relationships that are difficult to explain are the moderate relationship between Active Dorsiflexion Knee Extended and Occupation and Transport related physical activity and between Knee Extended Stretch Reflex and Role Emotional. It is possible that the small and eclectic nature of this sample is masking the quantitative relationships. It was also evident that an individual factor such as personal motivation was more influential than the person’s physical impairments on their participation in physical activity.

The qualitative interviews reveal the participants’ strong positive outlook toward participating in life roles. This perspective was also evident in the relationships between mental health (Vitality and Mental Health- SF-36v2) and overall physical activity in the context of home repair and housework.

The aims of this study were to better understand the influence of body structures and functions, activities and contextual factors on participation in physical activity in those with a CNS lesion resulting in lower limb spasticity. An additional aim is to better
understand the interaction between participation in physical activity and QOL. The measures of the study identify the impairments, the activity limitations and restrictions in participation among these individuals. The findings also reported a reduction in QOL due to inactivity.

The World Health Organization (2001, p.3) defines disability as “…an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual … and that individual’s contextual factors (environmental and personal factors)”. The broad range of measures, spanning all the domains of the ICF suggest that participants’ health conditions were negatively impacting their participation in physical activity across the life roles of recreation and leisure, work and employment, self care, and domestic life. The findings also suggest that some of this negative effect of their health conditions may be ameliorated through increased levels of individual support and enhanced access (e.g. programs and transport). Despite these barriers, individuals were finding ways to be somewhat active and were motivated to do more and overcome their functional limitations.

Many individuals with disabling conditions lead inactive lifestyles due to their impairments of multiple body functions and structures. These impairments typically lead to sedentary lifestyles. The findings of my study suggest that the participants had a positive outlook on life and were motivated to improve their health condition. However, they reported barriers that limited their participation. If these barriers were minimized participation in physical activity may increase. Also, if there were more programs and services available to these individuals they would likely benefit from these resources and have the opportunity to improve their health conditions. The findings of my study show that although these individuals had impairments they wanted to improve their physical functioning and increase their participation in life roles.

These individuals are highly motivated to participate in rehabilitation programs (e.g.: physiotherapy) to improve their health condition. The findings of this study show that despite their impairments these individuals were adhering to therapy programs. However, the participants expressed frustration with program accessibility reporting restrictions with transportation, program costs, and cutbacks. If these programs and
services were more accessible and available these individuals with disabilities would
benefit from these resources. If there were more programs available to accommodate
individuals with disabilities it would increase their opportunities. Potential funding for
these programs could be provided by grants/scholarships, and/or governing programs
such as the Vancouver Island Health Authority.

The findings of this study suggest that the major barriers to participating in
physical activity included situations where individuals were required to leave their homes
(e.g.: fear of falling outside when the weather was poor and transportation from their
homes to programs). If these barriers were minimized it is likely that participation among
individuals with disabilities would increase. Home-based exercise and therapy programs
could offer a solution to combating barriers that involve leaving the home. If individuals
are provided with daily exercises they could do in their own homes they are more likely
to be active. It is also important to educate family members and friends so they can
encourage and assist with these home based programs. Another way to reduce the fear of
falling and the lack of transportation is to provide programs where social workers make
home visits to help individuals with daily exercises and activities to encourage
participation. The fear of falling was a barrier among the study participants and this could
be minimized if a counseling approach was taken at therapy sessions to increase
confidence of these individuals. Finally, the findings imply that individuals could receive
educational resources (brochures, information, etc.) to encourage mobility and ways to
enhance their safety.

The motivation and positive outlook that was reported by the study participants
can be used to enhance self-efficacy toward participation in physical activity among
others. The study participants could potentially serve as role models. Vicarious
experience, seeing others perform an activity, is an important source of efficacy
information (Bandura, 1977). The general population, including those with and without
disabling conditions, could benefit from these positive perspectives to improve their own
health conditions (e.g.: get physically fit, join recreation/leisure programs). The low
levels of physical activity among most adults suggest they struggle to participate in the
required daily physical activity and/or to improve their health. However, it may be
motivating to see that despite the impairments that these participants live with everyday they stay positive and are eager to improve their health.
References


Kwan, M., Woo, J., & Kwok, T. (2004). The standard oxygen consumption value equivalent to one metabolic equivalent (3.5 ml/min/kg) is not appropriate for elderly people. *International Journal of Food Science and Nutrition, 55*(3), 179-182.


Appendix A: Active Knee Extended Range of Motion

PARTICIPANT ID#: ____________________

<table>
<thead>
<tr>
<th></th>
<th>PASSIVE</th>
<th>ACTIVE</th>
</tr>
</thead>
<tbody>
<tr>
<td>KNEE</td>
<td>KNEE FLEXED</td>
<td>KNEE EXTENDED</td>
</tr>
<tr>
<td>FLEXED</td>
<td>KNEE EXTENDED</td>
<td>KNEE FLEXED</td>
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<tr>
<td>Ankle</td>
<td>Indicate DF or PF</td>
<td>Indicate DF or PF</td>
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<td></td>
<td>Indicate DF or PF</td>
<td>Resting Attitude</td>
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<td></td>
<td>Indicate DF or PF END RANGE only</td>
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<tr>
<td></td>
<td></td>
<td>Indicate DF or PF END RANGE only</td>
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</tbody>
</table>

DATE:____________________ What side of the Body______________
Appendix B: Ankle Plantar Flexors Tone Scale

**Point of note**
- All tests are measured by passive dorsiflexion from position of maximum plantarflexion to position of maximum dorsiflexion.
- All tests are performed 3 times, and the highest score is recorded.
- Results of measurement are compared with the nonparetic side in the case of hemiplegia.
- Stretch reflex measures neurologic muscle reaction to passive movement.
- Middle range resistance measures resistance with passive movement, not including resistance of the final range.
- Final range resistance measures the resistance necessary to maintain the final position (i.e., excluding middle range resistance).

**Velocity of passive dorsiflexion**
- Stretch reflex: as fast as possible.
- Middle range resistance: as slow as possible.
- Final range resistance: as slow as possible.

**Position of measurement**
- All measurements are given for knee extended and knee flexed at 90° in a supine position.

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<table>
<thead>
<tr>
<th>Talo-crural</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
</tr>
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<tbody>
<tr>
<td>Forefoot</td>
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<tr>
<td>Knee ROM</td>
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</tbody>
</table>

*Yellow highlight was the values measured in this thesis*
● Beginning position of passive movement is the position of maximum ankle plantarflexion.
● When this method is difficult, the rater must record the difficulty.

**Score**

**Stretcher reflex.**
0: No twitch.
1: Twitch and no clonus.
2: Mild clonus, persisting _3s.
3: Moderate clonus, persisting 3–10s.
4: Severe clonus, persisting _10s.

**Middle range resistance.**
0: No resistance.
1: Mild resistance, slight increase in resistance.
2: Moderate resistance, greater increase in resistance.
3: Severe resistance, considerable increase in resistance, but able to achieve passive movement.
4: Passive movement is difficult.

**Final range resistance.**
0: No resistance.
1: Mild resistance, slight increase in resistance.
2: Moderate resistance, greater increase in resistance.
3: Severe resistance, considerable increase in resistance, but able to maintain final
4: Passive movement is difficult.
# Appendix C: Mini Mental State Examination

## MINI MENTAL STATE EXAMINATION

**Client Name** __________________________ **Assessor** __________________________ **Date** ____________

<table>
<thead>
<tr>
<th>Maximum Score</th>
<th>Score Achieved</th>
<th>Record client’s answers in the spaces provided</th>
</tr>
</thead>
</table>

### ORIENTATION:

| 5 | Q1 | What is the - Year ______ Season ______ Month ______ Day ______ Date ______ |
| 5 | Q2 | Where are we - Country ______ State ______ Town/City ______ Hospital/Street ______ Ward/House no. ______ |

### REGISTRATION:

| 3 | Q3 | Name these 3 objects - apple, penny, table. 1 second to say each. Then ask the person to repeat all three after you have said them. Score 1 point for each one correct on the first attempt. Repeat them (maximum 5 times) until he/she learns them. Count trials and record. Trials: ______ |

### ATTENTION AND CALCULATION:

| 5 | Q4 | Serial 7's: Count backwards from 100 by subtracting 7 (93 86 79 72 65) Score 1 point for each correct. (A correct response is one that is 7 less than the previous response even if the previous response is incorrect) Stop at 5 responses. - OR - Ask the person to spell the word “WORLD” forward and then backwards. Score 1 point for each letter in correct order. e.g. DLROW = 5, DLORW = 3 |

### RECALL:

| 3 | Q5 | Ask for the names of the three objects given to remember in Q3. Score 1 point for each correct answer irrespective of the order they are recalled in. apple penny table |

### LANGUAGE:

| 2 | Q6 | Show the person a “PENCIL” and a “WATCH”. Have the person name them as you point. Score 1 point for each correct answer. |
| 1 | Q7 | Have the person repeat the phrase - “NO IFS, ANDS, OR BUTS”. Score 1 point for a correct repetition. |
| 3 | Q8 | Have the person follow a 3 stage command. Take the paper in your right/left hand. Fold it in half once with both hands. Put it on the floor. Score 1 point for each part correctly executed. |

| 1 | Q9 | Read and obey the message. CLOSE YOUR EYES Score 1 point if the person closes their eyes. They do not have to read aloud. |
| 1 | Q10 | Ask the person to write a sentence of his/her own choice. The sentence should contain a subject and an object and make sense. Ignore spelling errors. |
| 1 | Q11 | Ask the person to copy the design. Score 1 point if all sides and angles are preserved and the intersecting sides form a quadrangle. |

### TOTAL SCORE

---


Compiled by Stephen Merrett. Mental Health Services For Older People, Country Liaison Service. March 2003
Appendix D: Visual Analogue Pain Scale

Numeric Rating Scale/Visual Analogue Scale

Date: ____________________________________________

Participant: ______________________________________

Participant ID#: __________________________________

Ask the patient to rate his or her pain by indicating with a mark on the line. The numeric value of 0 indicates no pain and 10 represents the worst pain imaginable. Verbally ask the patient each question and record pain location.

When you're walking, do you consistently have pain in any particular joint in your lower body?

Please rate your pain by indicating a mark on the line. The numeric value of 0 indicates no pain and 10 represents the worst pain imaginable.

1. On a scale of 0 to 10, with 0 being no pain at all and 10 being the worst pain imaginable, how would you rate your pain RIGHT NOW.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Pain</td>
<td>Worst Pain Imaginable</td>
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</tbody>
</table>

Pain Location: ______________________________________

2. On the same scale, how would you rate your USUAL level of pain during the last week.

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<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Pain</td>
<td>Worst Pain Imaginable</td>
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</tbody>
</table>
3. On the same scale, how would you rate your BEST level of pain during the last week.

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<tr>
<th>0</th>
<th>1</th>
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<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
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</tr>
</thead>
<tbody>
<tr>
<td>No Pain</td>
<td>Worst Pain Imaginable</td>
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</table>

4. On the same scale, how would you rate your WORST level of pain during the last week.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<tbody>
<tr>
<td>No Pain</td>
<td>Worst Pain Imaginable</td>
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Appendix E: Timed Get Up and Go test

**Equipment**
- straight-backed armchair with a seat height of 46 cm
- one pylon
- stopwatch
- measuring tape
- masking tape

**Positioning and preparation**
- Place a piece of tape 3 metres from the front of the chair and place the pylon on the middle of the tape.
- Ensure the chair is stable and will not move when the participant moves from sit to stand or sits down
- Participant should be wearing regular footwear, may use usual walking aid if needed, and sitting with their back resting on the back of the chair.

**Instructions to the participant**
"Sit with your back against the chair and your arms on the arm rests. On the word `go,' stand upright, then walk at your normal pace around the cone, walk back to the chair, and sit down."

**Timing**
The stopwatch is started on the word `go' and stopped when the participant has returned to the starting position.

**Interpretation**
Values for healthy older adults: 8.1 (7.1–9.0) seconds for 60 to 69 year olds, 9.2 (8.2–10.2) seconds for 70 to 79 years, and 11.3 (10.0–12.7) seconds for 80 to 99 years.
Appendix F: GaitRite Mat

**GAIT PARAMETERS:**

Participant: ________________________________
Date: ________________________________

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*Please mark the calendar date with an ‘X’ if you have any fall, including a slip or trip, in which you lost your balance and landed on the floor or ground or lower level.*

*For each fall marked above (i.e. each ‘X’), please complete a section below.*

---

**Date of Fall:**

**Location:** (e.g. garden, sidewalk, kitchen, bedroom)

**Activity:** (e.g. walking, standing, up/down stairs, turning)

**Cause:** (e.g. misjudgement, tripped, loss of balance, slipped)

**Weather and Time of day:** (e.g. morning, evening, rainy, icy)
Appendix H: Physical Activity Scale for Individuals with Physical Disabilities

APPENDIX H: PHYSICAL ACTIVITY SCALE FOR INDIVIDUALS WITH PHYSICAL DISABILITIES

Instructions: This questionnaire is about your current level of physical activity and exercise. Please remember there are no right or wrong answers. We simply need to assess your current level of activity.

Leisure Time Activity
1. During the past 7 days how often did you engage in physical activities such as reading, watching TV, computer games, or doing housework?
   1. Never (Go to question #2)
   2. Seldom (1–2)
   3. Sometimes (3–4)
   4. Often (5–7)

   What were these activities?
   On average, how many hours per day did you spend in these activities?
   1. Less than 1 hr
   2. 1 but less than 2 hr
   3. 2–4 hr
   4. More than 4 hr

2. During the past 7 days, how often did you walk, wheel, push outside your home or specifically for exercise, for example, getting to work or class, walking the dog, shopping, or other errands?
   1. Never (Go to question #3)
   2. Seldom (1–2)
   3. Sometimes (3–4)
   4. Often (5–7)

   On average, how many hours per day did you spend wheeling or pushing outside your home?
   1. Less than 1 hr
   2. 1 but less than 2 hr
   3. 2–4 hr
   4. More than 4 hr

3. During the past 7 days, how often did you engage in light physical activities such as bowling, golf with a cart, hunting or fishing, darts, billiards or pool, therapeutic exercise or occupational therapy, stretching, use of a standing frame or other similar activities?
   1. Never (Go to question #4)
   2. Seldom (1–2)
   3. Sometimes (3–4)
   4. Often (5–7)

   What were these activities?
   On average, how many hours per day did you spend in these activities?
   1. Less than 1 hr
   2. 1 but less than 2 hr
   3. 2–4 hr
   4. More than 4 hr

4. During the past 7 days, how often did you engage in moderate physical activities such as doubles tennis, softball, golf without a cart, ballroom dancing, wheelchair or pushing for pleasure or other similar activities?
   1. Never (Go to question #5)
   2. Seldom (1–2)
   3. Sometimes (3–4)
   4. Often (5–7)

   What were these activities?
   On average, how many hours per day did you spend in these activities?
   1. Less than 1 hr
   2. 1 but less than 2 hr
   3. 2–4 hr
   4. More than 4 hr

5. During the past 7 days, how often did you engage in strenuous sport and recreational activities such as jogging, wheelchair racing, running, off-road pushing, swimming, aerobic dance, arm wrestling, cycling (hand or leg), singles tennis, rugby, basketball, walking with crutches or braces, or other similar activities?
   1. Never (Go to question #6)
   2. Seldom (1–2)
   3. Sometimes (3–4)
   4. Often (5–7)

   What were these activities?
   On average, how many hours per day did you spend in these activities?
   1. Less than 1 hr
   2. 1 but less than 2 hr
   3. 2–4 hr
   4. More than 4 hr

6. During the past 7 days, how often did you do any exercise specifically to increase muscle strength and endurance such as lifting weights, push-ups, pull-ups, or wheelchair push-ups, etc.?
   1. Never (Go to question #7)
   2. Seldom (1–2)
   3. Sometimes (3–4)
   4. Often (5–7)

   What were these activities?
   On average, how many hours per day did you spend in these activities?
   1. Less than 1 hr
   2. 1 but less than 2 hr
   3. 2–4 hr
   4. More than 4 hr

7. During the past 7 days, how often have you done any light household work such as dusting, sweeping floors or washing dishes?
   1. Never (Go to question #8)
   2. Seldom (1–2)
   3. Sometimes (3–4)
   4. Often (5–7)

   On average, how many hours per day did you spend doing light household work?
   1. Less than 1 hr
   2. 1 but less than 2 hr
   3. 2–4 hr
   4. More than 4 hr

8. During the past 7 days, how often have you done any heavy household work or chores such as vacuuming, scrubbing floors, washing windows, or walls, etc.?
   1. Never (Go to question #9)
   2. Seldom (1–2)
   3. Sometimes (3–4)
   4. Often (5–7)

   On average, how many hours per day did you spend doing heavy household work or chores?
   1. Less than 1 hr
   2. 1 but less than 2 hr
   3. 2–4 hr
   4. More than 4 hr

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9. During the past 7 days, how often did you do house repairs or yard work? Scored PASIPD
1. Never (Go to question 9/10)
2. Seldom (1-2d)
3. Sometimes (3-4d)
4. Often (5-7d)
11. During the past 7 days, how often have you done yard work or yard care including mowing, weed or snow removal, tree or bush trimming, or weed chopping, etc? Scored PASIPD
1. Never (Go to question 11)
2. Seldom (1-2d)
3. Sometimes (3-4d)
4. Often (5-7d)
13. During the past 7 days, how often did you do outdoor gardening?
1. Never (Go to question 12)
2. Seldom (1-2d)
3. Sometimes (3-4d)
4. Often (5-7d)

Average Hours Per Day Calculation for Items 2-12

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<tr>
<td>Sometimes (3-4d)</td>
<td>1-3</td>
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</tr>
<tr>
<td>Often (5-7d)</td>
<td>&gt;4</td>
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Average Hours Per Day Calculation for Item 13

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<th>Category</th>
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<tr>
<td>Sometimes (3-4d)</td>
<td>1-3</td>
<td>1.6</td>
</tr>
<tr>
<td>Often (5-7d)</td>
<td>&gt;4</td>
<td>3.6</td>
</tr>
</tbody>
</table>

NOTE: PASIPD score = sum of item multiplier x average hours per day over items 2-13.

References
Appendix I: Quality of Life Short Form 36- Version 2 Survey

Appendix. SF-36 Questions

1. In general, would you say your health is:

2. Compared to one year ago, how would you rate your health in general now?

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
   a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports
   b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf
   c. Lifting or carrying groceries
   d. Climbing several flights of stairs
   e. Climbing one flight of stairs
   f. Bending, kneeling, or stooping
   g. Walking more than a mile
   h. Walking several blocks
   i. Walking one block
   j. Bathing or dressing yourself

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?
   a. Cut down the amount of time you spent on work or other activities.
   b. Accomplished less than you would like
   c. Were limited in the kind of work or other activities
   d. Had difficulty performing the work or other activities (for example, it took extra effort)

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?
   a. Cut down the amount of time you spent on work or other activities
   b. Accomplished less than you would like
   c. Didn’t do work or other activities as carefully as usual

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

7. How much bodily pain have you had during the past 4 weeks?

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks
a. Did you feel full of pep?
b. Have you been a very nervous person?
c. Have you felt so down in the dumps that nothing could cheer you up?
d. Have you felt calm and peaceful?
e. Did you have a lot or energy?
f. Have you felt downhearted and blue?
g. Did you feel worn out?
h. Have you been a happy person?
i. Did you feel tired?

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

11. How TRUE or FALSE is each of the following statements for you?
   a. I seem to get sick a little easier than other people
   b. I am as healthy as anybody I know
   c. I expect my health to get worse
   d. My health is excellent

**SF-36 Response Choices**

1. Excellent, Very Good, Good, Fair, Poor

2. Much better now than one year ago, Somewhat better now than one year ago, About the same as one year ago, Somewhat worse now than one year ago, Much worse than one year ago

3. Yes, Limited a lot; Yes, Limited a little; No, Not limited at all

4a–d. Yes, No

5a–c. Yes, No

6. Not at all, Slightly, Moderately, Quite a bit, Extremely

7. None, Very mild, Mild, Moderate, Severe, Very severe

8. Not at all, A little bit, Moderately, Quite a bit, Extremely

9. All of the time, Most of the time, A good bit of the time, Some of the time, A little of the time, None of the time

10. All of the time, Most of the time, Some of the time, A little of the time, None of the time

11. Definitely true, Mostly true, Don’t know, Mostly false, Definitely false

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Appendix J: Recruitment Script for VIHA Administrative Staff

The subsequent script will be followed by QACCH Spasticity Clinic Administrative Assistant when she/he has identified a potential participant for the study.

QACCH is currently involved in a study exploring the outcomes of receiving a combination of botox, physiotherapy and bracing on mobility and aspects of quality of life. This study is being conducted in conjunction with researchers from the University of Victoria. I believe you may meet the eligibility criteria to participate in the study. Participating or not participating in the study does not influence your access to or the type of treatment you will receive. Would you be interested in hearing more about this study to determine whether or not you are interested in participating?

Please know that if you do decide to participate, you may withdraw at any time without any consequences or any explanation and agreeing to hear more about the study does not commit you to participating.

If yes: May a member of the research team from contact you directly by phone?
Appendix K: Recruitment Script for UVic Researchers

Hello, this is [Name] from the University of Victoria calling on behalf of the study being conducted by Dr. Quartly and the University of Victoria. May I please speak with [contact]?

*a. Speaking or b. if new person comes to phone repeat beginning*

It is my understanding that [you or Name of client and contact if appropriate] is/are interested in hearing more about the study that was mentioned to you by Robin, Dr. Quartly’s receptionist.

*a. No. ....That’s fine, Dr. Quartly will see you at your scheduled appointment for your regular treatment or b. Yes.*

The aim of the study is to explore the outcomes of receiving the combination of therapies that you may be receiving, specifically Botox, physiotherapy and bracing on your mobility and quality of life. Our hope is that information gained from this study will help inform clinical practice in other regions.

There are a number of measures that will be taken over the course of your regular treatment over the next year that we would like your permission to track to determine whether there is a change. For example, the amount of movement you have at your ankle joint will be measured by Dr. Quartly and the physiotherapist. The treatment will be the same regardless of participation in the study.

In addition to the measures normally collected by the doctor, we would also like you to track your number of falls and complete two surveys about physical activity and quality of life. Each survey will be completed 4 times over the year.

At your first visit with Dr Quartly we would gather some of this information, so your appointment would be 1/2 an hour to 45 minutes longer. And you would have one extra visit of about 30 minutes after your initial assessment to confirm the initial measures.

These 2 surveys would then be completed at 6 months and at one year.

Are you interested in participating in the study? If you are not interested, this in no way affects your treatment.

*a. No. Thank you for your time, we hope your treatment goes well. b. YES. Great! The receptionist, Robyn, at the Spasticity clinic will either call to book the second appointment or she will do this at your scheduled assessment. Thank you and we will see you on [date].*
If leaving message:

Hello, this is [Name] from the University of Victoria calling on behalf of the study being conducted by Dr. Quartly and the University of Victoria.

I wanted to provide you with more information about the study. If possible could you please call 250-853-3144 and leave a message indicating when would be good time of day for me to contact you.

Thank you
Appendix L: Competent Adult Consent Form

[Department letterhead]  
Participant Consent Form – Competent Adults

Using Botulinum Toxin A, bracing and physiotherapy to treat spasticity in individuals with neurological conditions

You are being invited to participate in a study entitled “Using Botulinum Toxin A, bracing and physiotherapy to treat spasticity in individuals with neurological conditions” that is being conducted by the Queen Alexandra Spasticity Clinic and the School of Exercise Science, Physical Health and Education at the University of Victoria. The research team members are:

Dr Sandra Hundza  
Dr Viviene Temple  
Ms. Jill Dobrinsky  
Ms. Kim Choy  
Ms. Brayley Chow  
Ms. Iris Loots  
Ms. Jasmine Kim  
Dr Caroline Quartly  
Ms. Alexis Hampshire  
Mr. Jamie Dunnett  
Ms. Pat Whitby-Bailey  
Mr. Gray Eakins  
Ms. Lynn Purves  

University of Victoria  
University of Victoria  
University of Victoria  
University of Victoria  
University of Victoria  
University of Victoria  
University of Victoria  
VIHA and the Queen Alexandra Spasticity Clinic  
VIHA and the Queen Alexandra Spasticity Clinic  
VIHA and the Queen Alexandra Spasticity Clinic  
VIHA and the Queen Alexandra Spasticity Clinic  
VIHA and the Queen Alexandra Centre

Please feel free to contact Dr. Hundza at (250) 721-8387 <shundza@uvic.ca> or Dr. Temple at (250) 721-8373 <vtemple@uvic.ca> if you have any questions.

The project will evaluate the effects of using a combination of therapy methods (Botulinum Toxin A, bracing, and physiotherapy) being provided by the Spasticity Clinic to improve mobility and increase quality of life for people experiencing spasticity; where muscles are overactive and tight. University of Victoria researchers will work with the Spasticity Clinic staff to evaluate the effects of the combination therapy on movement of the ankle joint, your ability to move around, pain, physical activity, and how you feel about your health (health-related quality of life).

Spasticity management is important to improve mobility, decrease pain, increase physical activity, and enhance quality of life and this has benefits to
overall health. The benefits of this combination of therapies has not be established.

You are being asked to participate in this study because you will be receiving this combination of therapies for spasticity in your lower limb. The therapies are provided as part of your normal clinical care and are independent of the research study. Each participant’s involvement in the study will occur over a 14 month period which coincides with your therapy at the Spasticity Clinic. If you agree to voluntarily participate in this research, your participation will involve completing the following: quality of life and physical activity questionnaires (collected four times) and a record of falls (if a fall occurs at each visit). We will also require access to assessment data routinely collected by the Spasticity Clinic clinicians at each appointment; specifically: movement of the ankle joint, measures of mobility (e.g. walking speed), pain, and spasticity. These measures and when each will be recorded are outlined in the 2 pages attached to this consent form. All therapy and assessment will be conducted at the Queen Alexandra Spasticity Clinic.

There is some inconvenience to you from this research. To establish a baseline level of functioning and mobility we will ask you to complete all of the measures prior to the your therapy commencing. There is the possibility that you may uncomfortable answering questions about physical activity and quality of life. You do not have to answer any questions you do not wish to.

Participation in this research must be completely voluntary and we will confirm your ongoing consent every three months. Choosing not to participate in this study will in no way affect your clinical therapy or access to Spasticity Clinic services (i.e. treatment received will be the same whether you choose to participate or not). If you decide to participate, you may withdraw at any time without any consequences or any explanations. Choosing to withdraw from the study will in no way effect your therapy or access to the Queen Alexandra Spasticity Clinic. The Spasticity Clinic health care professionals (i.e. doctor, physiotherapist, and orthotist) will be providing your clinical care and are part of the research team; however these health care professionals will not be involved in the recruitment or consent process. If you do withdraw from the study your data will be used for statistical analysis if you give your permission to use your data, but the data will be destroyed if you do not give permission.
Your confidentiality and the confidentiality of the data will be protected by removing identifying information from the assessment as by using numerical codes for the data rather than names. Data will be stored in a locked cabinet or a password protected computer in the Institute of Physical Activity and Health Research at the University of Victoria. Electronic data will be erased and the paper files will be shredded after 5 years from the completion of the study.

A report of the findings of this study will be provided to the health care clinicians of the Vancouver Island Health Authority. We also anticipate that the findings will be presented at scientific conferences and published in scholarly journal articles and in graduate student theses. If you are interested in receiving a copy of the final report you may upon request. You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca and the VIHA Research Ethics office at 250-370-8620.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

___ Name of Participant ___ Signature ___ Date ___

Ongoing consent 1

___ Name of Participant ___ Signature ___ Date ___
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<tr>
<td>Ongoing consent 3</td>
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<tr>
<td><strong>Name of Representative</strong></td>
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</table>

*A copy of this consent will be left with you, and a copy will be taken by the researcher.*
Using Botulinum Toxin A, bracing and physiotherapy to treat spasticity in individuals with neurological conditions.

[Name] is being invited to participate in a study entitled “Using Botulinum Toxin A, bracing and physiotherapy to treat spasticity in individuals with neurological conditions” that is being conducted by the Queen Alexandra Spasticity Clinic and the School of Exercise Science, Physical Health and Education at the University of Victoria. The research team members are:

- Dr Sandra Hundza, University of Victoria
- Dr Viviene Temple, University of Victoria
- Ms. Jill Dobrinsky, University of Victoria
- Ms. Kim Choy, University of Victoria
- Ms. Brayley Chow, University of Victoria
- Ms. Iris Loots, University of Victoria
- Ms. Jasmine Kim, University of Victoria
- Dr Caroline Quartly, VIHA and the Queen Alexandra Spasticity Clinic
- Ms. Alexis Hampshire, VIHA and the Queen Alexandra Spasticity Clinic
- Mr. Jamie Dunnett, VIHA and the Queen Alexandra Spasticity Clinic
- Ms. Pat Whitby-Bailey, VIHA and the Queen Alexandra Spasticity Clinic
- Mr. Gray Eakins, VIHA and the Queen Alexandra Spasticity Clinic
- Ms. Lynn Purves, VIHA and the Queen Alexandra Centre

Please feel free to contact Dr. Hundza at (250) 721-8387 <shundza@uvic.ca> or Dr. Temple at (250) 721-873 <vtemple@uvic.ca> if you have any questions.

The project will evaluate the effects of using a combination of therapy methods (Botulinum Toxin A, bracing, and physiotherapy) being provided by the Spasticity Clinic to improve mobility and increase quality of life for people experiencing spasticity; where muscles are overactive and tight. University of Victoria research researchers will work with the Spasticity Clinic staff to evaluate the effects of the combination therapy on movement of the ankle joint, the ability to move around, pain, physical activity, and how clients feel about their health (health-related quality of life). Spasticity management is important to improve mobility, decrease pain, increase physical activity, and enhance quality of life and this has benefits to
overall health. The benefits of this combination of therapies has not be established.

[Name] is being asked to participate in this study because [he/she] will be receiving this combination of therapies for spasticity in their lower limb. The therapies are provided as part of [Name’s] normal clinical care and are independent of the research study. Each participant’s involvement in the study will occur over a 14 month period which coincides with [Name’s] therapy at the Spasticity Clinic. If [Name] agrees to voluntarily participate in this research, [his/her] participation will involve completing the following: quality of life and physical activity questionnaires (collected four times) and a record of falls (if a fall occurs) at each visit. We will also require access to assessment data routinely collected by the Spasticity Clinic clinicians at each appointment; specifically: movement of the ankle joint, measures of mobility (e.g. walking speed), pain, and spasticity. These measures and when each will be recorded are outlined in the 2 pages attached to this consent form. All therapy and assessment will be conducted at the Queen Alexandra Spasticity Clinic.

There is some inconvenience to [Name] from this research. To establish a baseline level of functioning and mobility we will ask [Name] to complete all of the measures prior to the your therapy commencing. We anticipate that these baseline assessments will take approximately two hours (3 x 45 minute visits). We also anticipate that the questionnaires and record of falls will require between 10 and 30 minutes of [Name’s] time at [his/her] regular visits.

There is the possibility that [Name] may uncomfortable answering questions about physical activity and quality of life. [He/she] does not have to answer any questions [he/she] does not wish to.

Participation in this research must be completely voluntary and we will confirm [Name’s] ongoing assent and your consent every three months. Choosing not to participate in this study will in no way affect [Name] clinical therapy or access to Spasticity Clinic services (i.e. treatment received will be the same whether [Name] chooses to participate or not). If [Name] decides to participate, [he/she] may withdraw at any time without any consequences or any explanations. Choosing to withdraw from the study will in no way effect [Name’s] therapy or access to the Queen Alexandra Spasticity Clinic. The Spasticity Clinic health care professionals (i.e. doctor,
physiotherapist, and orthotist) will be providing your clinical care and are part of the research team; however these health care professionals will not be involved in the recruitment or consent process. If [Name] does withdraw from the study [his/her] data will be used for statistical analysis if you and [Name] give your permission to use the data, but the data will be destroyed if permission is not given.

[Name’s] confidentiality and the confidentiality of the data will be protected by removing identifying information from the assessment as by using numerical codes for the data rather than names. Data will be stored in a locked cabinet or a password protected computer in the Institute of Physical Activity and Health Research at the University of Victoria. Electronic data will be erased and the paper files will be shredded after 5 years from the completion of the study.

A report of the findings of this study will be provided to the health care clinicians of the Vancouver Island Health Authority. We also anticipate that the findings will be presented at scientific conferences and published in scholarly journal articles and in graduate student theses. If you are interested in receiving a copy of the final report you may upon request. You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca and the VIHA Research Ethics office at 250-370-8620.

Your signature below indicates that you understand the above conditions of [Name’s] participation in this study and that you have had the opportunity to have your questions answered by the researchers. Your signature below also indicates that you will attempt attend future visits. If this is not feasible, you will be willing to provide verbal consent via telephone prior to each visit.

____________________________________________________
Name of Participant

____________________________________________________
Name of Representative    Signature    Date
Ongoing consent 1

____________________  ______________________  ______________________
Name of Representative  Signature  Date

Ongoing consent 2

____________________  ______________________  ______________________
Name of Representative  Signature  Date

Ongoing consent 3

____________________  ______________________  ______________________
Name of Representative  Signature  Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.
Using Botulinum Toxin A, bracing and physiotherapy to treat spasticity in individuals with neurological conditions.

You are being invited to participate in a study called “Using Botulinum Toxin A, bracing and physiotherapy to treat spasticity in individuals with neurological conditions” that is being carried out by the Queen Alexandra Spasticity Clinic and Sandra Hundza and Viviene Temple from the University of Victoria. If you have any questions you can telephone Sandra at (250) 721-8387 or Viviene at (250) 721-873. There are three student assistants from the University helping with the project.

You will be receiving three treatments to reduce the spasticity in your leg at the Spasticity Clinic. The three treatments are 1) Botulinum Toxin A injections, 2) bracing, and 3) physiotherapy. You will be helping us learn how useful these therapies are improving people’s ability to walk and how this affects activity levels and how you feel about your health.

You are being asked to participate in this study because you will be receiving the three therapies for spasticity in your lower limb; where muscles your muscles are tight. If you agree to participate in this project, your participation will involve completing two surveys and recording any falls that occur over a 14 month period. The two surveys are a Quality of Life questionnaire and a Physical Activity questionnaire; and we will ask you to complete the surveys four times across the 14 months. Someone who know you can assist with the surveys. There is the possibility that you may uncomfortable answering questions about falls, physical activity or quality of life. You do not have to answer any questions you do not want to.

We also want to use information about movement of your ankle joint, walking and mobility, pain, and spasticity that is routinely collected by the Spasticity Clinic clinicians at each appointment. All therapy and assessment will be conducted at the Queen Alexandra Spasticity Clinic.
Participating in this project will take up some of your time. At the beginning of the project we will have three meetings of 45 minutes; and during the rest of the project we will meet every six weeks for 40 minutes.

Participation in this research must be your choice we will ask you whether you want to continue in the project every three months. Choosing not to participate in this study will in no way affect your clinical therapy or access to Spasticity Clinic services (i.e. treatment received will be the same whether you choose to participate or not). If you decide to participate, you may stop at any time without any consequences or any explanations. Choosing to withdraw from the study will in no way affect your therapy or access to the Queen Alexandra Spasticity Clinic. If you do withdraw from the study your data will be included in the project if you say we can, but the data will be destroyed if you do not give permission.

We won’t tell other people your answers to the surveys and we won’t use your name when we write up our information. Sandra and Viviene will lock up the information in cabinets in their offices. The information will be on a computer, but your name won’t be on the computer. Only Sandra, Viviene, and the three student assistants from the University will look at the answers. Five years from the end of the project we will destroy the information. After the project has finished, we will share what we learned about reducing spasticity. A report about the project will be provided to the health care clinicians of the Vancouver Island Health Authority. We will talk about it at meetings so other people learn from the study. We will write about it in professional magazines and three students will write reports for the University about the study. If you want, we will share the information with you.

You may check the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca and the VIHA Research Ethics office at 250-370-8620.

Your signature below indicates that you wish to participate in the project and that you have had the opportunity to have your questions answered by the researchers.
A copy of this consent will be left with you, and a copy will be taken by the researcher.
Appendix O: Open-ended Physical Activity Questions to Elicit Barriers and Facilitators

We are curious about things that have made physical activity more or less difficult since you last completed the physical activity questionnaire.

1) Are there things that have helped you be more active or any barrier to physical activity that you’ve experienced during the last 3 months?

Prompt: were there things about your health that made it easier or more difficult?

Prompt: did other people influence your level of physical activity?

 Probe: How did [Name/role] help/hinder?

Prompt: was there new equipment or new programs?

Prompt: or did you have difficulty getting to activity programs?

Probe: can you tell me about the…new program, difficulty with access etc.

2) So in general would you say that since they last time you completed the physical activity questionnaire have you been more active, less active or about the same?
## Appendix P: The SF-36v2 Questions that Make up the Scores for each Health Domain

<table>
<thead>
<tr>
<th>Code</th>
<th>Variable</th>
<th>Question #</th>
<th>Range of item response</th>
<th>Range of sub-scale response</th>
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<tr>
<td>HT</td>
<td>Health compared to one year ago</td>
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<td>1 to 5</td>
<td>1 to 5</td>
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<tr>
<td>PF</td>
<td>Physical Functioning</td>
<td>3</td>
<td>1 to 3</td>
<td>10 to 30</td>
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<tr>
<td>RP</td>
<td>Role Physical</td>
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<td>1 to 5</td>
<td>4 to 20</td>
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<tr>
<td>BP</td>
<td>Bodily Pain</td>
<td>7 &amp; 8</td>
<td>1 to 6</td>
<td>2 to 12</td>
</tr>
<tr>
<td>GH</td>
<td>General Health</td>
<td>1 &amp; 11</td>
<td>1 to 5</td>
<td>5 to 25</td>
</tr>
<tr>
<td>VT</td>
<td>Vitality</td>
<td>9a, 9e, 9j, 9i</td>
<td>1 to 5</td>
<td>4 to 20</td>
</tr>
<tr>
<td>SF</td>
<td>Social Functioning</td>
<td>6 &amp; 10</td>
<td>1 to 5</td>
<td>2 to 10</td>
</tr>
<tr>
<td>RE</td>
<td>Role Emotional</td>
<td>5</td>
<td>1 to 5</td>
<td>3 to 15</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9b, 9c, 9d,</td>
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<tr>
<td>MH</td>
<td>Mental Health</td>
<td>9f, 9h</td>
<td>1 to 5</td>
<td>5 to 25</td>
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## Appendix Q: Individual Averages for the Body Functions and Structures

### Assessments

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Active Knee Extended ROM</th>
<th>PFTS-Knee Extended</th>
<th>Visual Analogue Scale</th>
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<tr>
<td></td>
<td></td>
<td>Stretch Reflex Resistance</td>
<td>Middle Range Resistance</td>
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<td>18.00 PF</td>
<td>2.00</td>
<td>2.00</td>
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<td>7.50 PF</td>
<td>2.00</td>
<td>2.00</td>
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Appendix R: Individuals Average Scores for Functional Mobility Assessments

<table>
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<tr>
<th>Participant ID</th>
<th>TUG (sec)</th>
<th>GAITrite (cm/s)</th>
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<td>2</td>
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<td>1</td>
</tr>
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<td>3</td>
<td>Non-Ambulatory</td>
<td></td>
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</tr>
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<td>4</td>
<td>12.37</td>
<td>97.73</td>
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<td>5</td>
<td>18.14</td>
<td>65.75</td>
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</tr>
<tr>
<td>6</td>
<td>42.81</td>
<td>19.22</td>
<td>1</td>
</tr>
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<td>7</td>
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<td>130.45</td>
<td>0</td>
</tr>
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<tr>
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<td>8.87</td>
<td>107.90</td>
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Appendix S: Participant #8 Physical Activity Interview

Interviewee: #8

Assessment 3

Interviewer: what we are interested is in things that get in the way with participation in physical activity or barriers to physical activity. So can you think of the things that you do in terms of physical activity and tell me a bit about what they are

Interviewee: well I might walk to the store or do things like that or take care of my daughter and that’s all I do I don’t do anything strenuous or anything like that

Interviewer: so walking to the store is that very far

Interviewee: no that’s not very far and I have to feel confident to do it and I don’t go if I don’t. I take medication during the day and often I can tell if im okay to walk ot the store and also depends if it’s a nice day

Interviewer: so one way or another your health can get in the way?

Interviewee: yes, yes

Interviewer: so besides walking. Are there any household things that you do as well

Interviewee: yes yes I clean the house, I still do that. My girl friend does the heavy stuff but I do the light house work fore sure. Dishes, sweep the floors

Interviewer: yeah, yeah and taking care of daughter, are there activities involved in that

Interviewee: yes I have to cook, clean and do the dishes and just keep feeding her all day

Interviewer: how old is she

Interviewee: she is 13 and almost 6 feet. I am 6’7 and her mom is 6 feet

Interviewer: ohh wow, and u mentioned the weather

Interviewee: yeah and it depends on the weather, I wont go out if its raining because I cant hold my umbrella and cane at the same time and its more dangerous. I’d take the car if its raining and if its sunny ill take a walk

Interviewer: oh ok

Interviewee: and I do stairs at home too. Im trying ot use the stairs for my legs and for Kristine’s (girlfriend) weight.

Interviewer: ohh okay. So you use the stairs to get to one level of your house to another

Interviewee: yes I go right to the bottom level. And I use to live on the second floor so it’s a bit of exercise for me
Interviewer: so why have you decided to do stairs

Interviewee: well just because I am doing this study and I want to get better. I want ot get my muscles working again

Interviewer: So walking, doing housework and looking after the 13 year old sounds pretty busy. So do you have any exercises from physio or Occupational Therapist’s or anything like that?

Interviewee: no no

Interviewer: okay so nothing like that. So are there things besides the weather that may stop you from being as active as you would like maybe access to things or the cost of things

Interviewee: well we are waiting for our income taxes to be done so we can get a re assessment so we go to the pool and get a pool pass. so its kind of a hassel

Interviewer: ohh so that’s a tax thing

Interviewee: you have to show them how much you make

Interviewer: oh so then you can become eligible to go

Interviewee: yes yes to go to the pool once a week for 52 weeks, its like 6 bucks to go so its too expensive to go. My daughter and I have been to the pool a few times

Interviewer: so it sounds like you are getting motivation to get out. So where you more active before

Interviewee: yes totally fore sure. I did tons of sports through my teen years, even into my twenties.

Interviewer: So your health is really impacting what …

Interviewee: yeha yeah, my muscles feel really weak and im just trying to get my muscles going again. All the ones that I forgot over the years.

Interviewer: yeah yeah

Interviewee: my legs are really stiff. I had a really bad injury on this leg when I pulled my hamstring and my whole leg went all purple. I never felt like it really completely, you know when you can get a really good stretch on your hamstring I have never had that since I tried that it scares me but when I do the stairs at home I can feel it just a little bit

Interviewer: yeah. So it sounds like you may have confidence issues, slippery?

Interviewee: yes yes

Interviewer: have you had falls

Interviewee: yes
Interviewer: related to being active

Interviewee: no.. well because of the MS, well yeah I guess. Well just walking in general like going to the bathroom, being in the shower, I have fallen in the shower, getting in and out of the shower, falling in the tub, falling getting off the toilet, getting on the toilet, falling on the floor, tripped on the carpet, going to the couch. This and that, I have had lots of falls. I am a good faller, I can fall and not hurt myself.

Interviewer: yes, yes have you taught yourself how to fall

Interviewee: oh yeah

Interviewer: because there are actually problems that teach you how to fall

Interviewee: yeah yeah

Interviewer: so it sounds like a survival skill you have taught yourself. So are there other things that get in the way, cost, weather, health

Interviewee: well I want to start physio too but I think it cost me money. So im not sure about that. That’s about it

Interviewer: yeah, yeah

Interviewee: and im not confident because I don’t like to fall and I cant do long distance

Interviewer: so it will be a motivator then

Interviewee: yeah yeah, a motivator so I am interested to see what happens

Interviewer: so your getting botox today

Interviewee: yeah yeah I am interested in seeing what happens

Interviewer: so is there anything else that you would like to add about participation in physical activity

Interviewee: well I would like to go to the pool, and I don’t like waiting for my taxes to be done

Interviewer: okay good good thank you very much

Interviewee: also I like to garden outside in the nice weather

Interviewer: great, great, okay well great thank you very much