

Examining the Relationship between Chronic Pain and Health Related Quality of
Life Among Older Canadian Adults with Disability

by

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Abstract

Introduction: The effects of chronic pain on health-related Quality of Life (HRQoL) among older Canadian adults with disability was not well known.

Study Objectives: This study was conducted to examine the relationship between chronic pain and HRQoL among older Canadian adults with disability aged 55+.

Methods: This study was a secondary analysis of cross-sectional data from the 2006 Participation and Activity Limitation Survey (PALS). Weighted data was used to examine the relationship between chronic pain and HRQoL using multivariate logistic regression techniques.

Results: An estimated 68% of older Canadian adults with disability reported having chronic pain. Multivariate regression analysis confirmed a significant independent effect of chronic pain on self-reported HRQoL.

Conclusion: Our results highlight the importance of pain assessment and management for older adults with disabilities in general and in particular among those with limited communication abilities.

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Dedication

I dedicate this thesis to my mother Alexandra Zawaly and my grandmother Margaret Karpetz.

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List of Abbreviations

ANS	Autonomic Nervous System
AOR	Adjusted Odds Ratio
CNS	Central Nervous System
CP	Cerebral Palsy
HALS	Health and Activity Limitation Survey
HRQoL	Health Related Quality of Life
HRSDC	Human Resources Social Development Canada
IASP	The International Association for the Study of Pain
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disability and Handicaps
OR	Odds Ratio
MCS	Mental Component Summary
MOS	Medical Outcomes Study
PALS	Participation and Activity Limitation Survey
PCS	Physical Component Summary
QoL	Quality of Life
RDC	Research Data Centre
SCI	Spinal Cord Injury
SF-36	Short-Form Health Survey 36
SPSS	Statistical Package for Social Sciences
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organization

Examining the Relationship between Chronic Pain and Health Related Quality of Life Among Older Canadian Adults with Disability

The current research investigated the relationship between chronic pain and health related quality of life (HRQoL) among older Canadian adults with disability. The purpose was to further the understanding of how the HRQoL of older adults with disability is affected by the presence of chronic pain. Statistics Canada's Participation and Activity Limitations Survey (PALS) 2006 is the data set that was used to examine this relationship. The data analysis consisted of HRQoL as the outcome variable. Following a review of the literature it was found that there was very little research regarding chronic pain, HRQoL and disability. The research, which was available, did not focus on older adults with disability experiencing chronic pain and its effects on HRQoL; therefore, this research will address this gap in the literature.

Section 1 Introduction

Since 2010, the Canadian population has been aging at an accelerated rate and this will continue to take place until 2031 at which time the baby boom generation will reach the age of 65. It is projected that in Canada by 2036 there will be between 9.9 and 10.9 million older Canadians and they will represent approximately one quarter of the population. As Canadian adults age, they are more likely to have disabilities (Statistics Canada, 2009). It has been found that disability in older adults is a frequent occurrence (Heikkinen, 2003). The evidence of this has already begun to transpire, as in Canada in 2006, the overall rate of disability among Canadians (of all ages) was 14.3%, and among older adults (i.e., 65 years of age or older) was 43.4% (Statistics Canada, 2007b). In 2001, it was found that almost seven out of every ten Canadians with disability had pain related disability (Statistics

Canada, 2001). Chronic pain is known as a pain-related disability (Turner, Jensen, Warm, & Cardenas, 2001). There is evidence that chronic pain becomes a common problem in the older adult population (Brattberg, Parker, & Thorslund, 1996; Brochet, Michel, Barberger-Gateau, & Dartigues, 1998; Elliott, Smith, Penny, Smith, & Chambers, 1999; Blyth, et al., 2001; Helme & Gibson, 2001b; Smith, et al., 2001). Some researchers including Rummans and colleagues (1998) and Anderson and colleagues (1999) suggested that pain is one of the most dominant determinants of an individual's quality of life (QoL). Several studies have demonstrated that there is a dose-response relationship between chronic pain and QoL; that relationship being that as one increases the other correspondingly decreases (Hunfeld et al., 2001; Cleeland & Ryan, 1994; Becker et al., 1997). Based on numerous studies of the general population, or population of older adults in general (e.g., Becker, et al., 1997; Hill, Parson, Taylor, & Leach, 1999; Haythornthwaite & Benrud-Larson, 2000), it has been determined that regardless of the source of chronic pain, the QoL is negatively affected. Therefore, due to changes in the demographics in the older Canadian adult population, it is becoming even more important to research and understand the experiences of those older Canadian adults living with disabilities in order to put appropriate policy and programming into practice.

1.1 Research Objectives

The goal of this research is to examine the association between chronic pain and HRQoL while controlling for sociodemographic and disability related factors.

The main objectives of this research are: 1) to describe the prevalence of chronic pain among older Canadian adults with disability, 2) to examine the relationship between

chronic pain and health related quality of life, 3) to assess if there is a dose-response relationship between chronic pain and HRQoL.

To achieve these objectives, the study sample of older adults with disability was deduced from the adult survey of PALS, 2006, which is the primary source of disability data in Canada.

1.2 Hypothesis

This research tested the following two hypotheses: 1) older adults living with disability who reported chronic pain will have poorer HRQoL compared to those older adults living with disability who are free from chronic pain, 2) there is a dose-response relationship between chronic pain and HRQoL among older Canadian adults with disability.

Section 2 Theoretical/Conceptual Framework

2.1 Disability Models and Definitions

There are approximately 650 million people in the world living with disability, which makes up the world's largest minority (United Nations, 2006). The term "disability" has no definition that is unilaterally accepted (Bigby, 2002). The concept of disability does contain a distinct set of traits; however, it does not provide a simplistic definition describing what it is and who can be categorized as having a disability (European Disability Forum, 2002; Harriss-White, 1996). The World Health Organization (WHO), defines disability to be "a restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1992). The United Nations added to the WHO's definition stating, "disabilities are descriptions of disturbances in function at the level of the person" (United Nations, 1990). Those in the Faculties of Disability Studies and/or those in Medicine conduct the majority of research

regarding impairment and disability. The division between the two Faculties is the interpretation of the term disability. The difference in the definition of disability complicates and leads to confusion in the meaning of the term, which is used in everyday language and often found written in literature (Altman, 2001). The terminology, which is currently used, is also significant because accepted definitions of disability have the potential to influence how others view disability and ultimately how disabilities are understood (Wendell, 1996).

Disability Studies use a social oppression paradigm to describe disability as the loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers (Northern Officers Group, 1999). Medical definitions focus on the theoretical degree of mental and/or physical health of an individual's ability to function (Gadacz, 1994). Therefore, one can deduce from these two different definitions that there are two opposing models used to describe disability. There are several theories that are used to examine disability; however, the most prominent are the medical model, sometimes referred to as the individual model of disability and the social model of disability (Oliver, 1996).

In terms of its impact, the medical model of disability is known to be the most significant (Oliver, 1996). It is indicated by Oliver (1996) that this model is reinforced by the "personal tragedy theory of disability" and the medicalization of disability. The medical model views the individual with disability as a "problem" that needs to be fixed in order to become as "normal" as possible (Cole, 2006). Therefore, the medical model of disability considers the "problem" of disability to be within the individual (Oliver, 1996). Thus, the medical model's underpinning is the belief that a "normal" function is necessary for humans to support "normal" life. Socially acceptable norms are established; however, any deviation

from “normal” is not acceptable. This is therefore, a normative assumption that moves further away from an individuals’ physiological state and incorporates certain values that would be approved by the greater society. This model views disability as something that must be prevented and if it cannot be prevented then other measures must be implemented such as curing. If curing does not work, the next and final measure is rehabilitation (Michalko, 2002). This illustrates the flaw of the medical model, which has at its foundation as the individual who possesses a disability is responsible for such disability.

The social model of disability began to take shape in the United Kingdom in the 1970’s with disability activists and the creation of the Union of the Physically Impaired Against Segregation (UPIAS) (Barnes & Mercer, 2004). The social model of disability is a term coined in the 1980’s by Michael Oliver and it is a central component of Disability Studies. The social model of disability is vigorously debated and challenged; and has primarily focused on the practical and conceptual use (Thomas, 2007). The social model of disability views disability as a social state caused by society not an anatomical or physiological state caused by the individual’s body (Stellman, 1983). The social model of disability states that disabilities are not something that can be cured by medical intervention because they are caused by society. The view of the social model of disability is that there is a dichotomy between impairments and disability, which opposes the medical model and its views of impairment and disability as one. The most common definition of disability used by the social model of disability is from UPIAS 1976:114 which states: disability is the disadvantage or restriction of activity caused by a contemporary organization which takes little or no account for people who have physical impairments and thus excludes them from participation in the mainstream of social activities (as cited in Greig, Lewins, & White,

2003). This definition of disability does not ignore the fact that individuals can have mental or physical impairments; however, its foundation is that the barriers these individuals face are caused by society and the lack of supports provided to allow them to lead successful lives. Limitations are caused by societal stereotypes that depict individuals with disabilities as helpless, needy, poor, or pathetic and who require the rest of society to help them (Bowe, 1978). Moreover, limitations are created by barriers in the social environment, which do not allow equal access for all (Bowe, 1978).

The social model of disability would state that disability is a social problem caused by society's lack of creating accommodations, which then result in the individual experiencing the state of disability. The social model of disability is contrary to the medical model of disability. Believers in the medical model of disability would say that disability is caused by an individual's physical or mental condition. However, the social model of disability would state that disability is not a medical condition and is in actuality a social state that is not curable by medical professionals.

It is clear that the medical and social models of disability are at two very different ends of the spectrum when defining disability. There has been a combination of these two very extreme theories, which views disability as the experience of the interaction between the physical environment, social, political, cultural, economic, functional limitation, and/or personal characteristics (gender, age, level of education), which can result in a disadvantage (Human Resources and Social Development Canada, 2006).

For 30 years prior to the Classification of Functioning, Disability and Health (ICF) there were two dominant disability frameworks, the International Classification of Impairments, Disability and Handicaps (ICIDH) and Nagi's Disablement Model also known

as functional limitation paradigm (Mitra, 2006). In addition, to the ICIDH and Nagi's Disablement Model, a third model was developed by the elaboration of the dimensions of Nagi's model as its framework known as the disablement model of Verbrugge and Jette (1994) which was also used in research and literature to describe disability. Nagi's model and the disablement model of Verbrugge and Jette were not created to specifically incorporate the social and medical models of disability; they were used to explain disability in the literature.

Nagi's model outlines how active pathologies become physical impairments that then result in disability (Nagi, 1965). According to Nagi's model, disability is the limitation in performance of socially defined tasks and roles within a physical and sociocultural environment that is related but not analogous to functional limitations, impairment, and pathology (Nagi, 1991). Nagi (1991) defines the terms as: functional limitations: restrictions in the basic physical or cognitive performance of the person, impairment: anatomical, intellectual, physiological, emotional loss or abnormality at the tissue, organ or body system, pathology: the interruption of normal cellular processes and the effort of the organism to regain a normal state.

The disablement model of Verbrugge and Jette (1994) was another framework of disability that had been implemented as a common conceptual framework for specifically researching disability in the older adult population. It was also a further development of Nagi's model (WHO, 1999). Verbrugge and Jette (1994) extended Nagi's model to include a complete sociomedical perspective to take in to account environmental and personal factors that influence the process of disablement. The Verbrugge and Jette model focuses its

attention to the dynamic feature of disablement and on the process that leads to disability and its factors, which change over time.

In 1980, the World Health Organization (WHO) created the first disability specific classification system known as the ICDH. The ICDH was created as a linkage to incorporate both the medical and social model of disability (Reynolds & Fletcher-Janzen, 2006), and to move away from the biomedical perspective of disability (Thomas, 2002). The ICDH also displayed a significant step forward when disabled individuals were no longer only depicted in a clinical setting and would now be socially included in the greater community (Hahn, 2002). The ICDH was created to establish a common jargon for examining disability (Duckworth, 1984). The ICDH also provided a clear distinction between impairments, disability, and handicaps. Impairment is described as any loss, or abnormality of psychological, physiological or anatomical structures or functions. Disability is described as any limitation or loss (due to an impairment) of ability to perform an activity or variations in the way considered normal for a human being. Handicap is described as a disadvantage experienced by a particular individual due to an impairment or a disability that limits or prevents the opportunity to fill a “normal” role in relation to age, gender and sociocultural factors for that particular individual (WHO, 1980) (Appendix A).

The definitions provided above display a significant relationship to one another. Handicap is a relationship between impairment and/or disability; therefore, handicap is only possible in the presence of an impairment or disability or both. Thus, handicap is an examination the individuals’ life experiences. Even though the ICDH was created to act as a linkage between the medical and social model of disability, the definitions of the three terms suggests a lack of the implementation of the social model of disability (Chamie,

1995). The three terms presented are defined by the concept of “normal”; therefore, the ICIDH has been criticized for maintaining the views of the medical model of disability (Oliver, 1996).

The terminology such as “disability” and “handicap” used in the ICIDH caused much disapproval (Brandsma, Lakerveld-Heyl, Van Ravensberg, & Heerkens, 1995). Bury (1997 & 2000), one of the creators of the ICIDH, presents the idea that the use of the definition “handicap” views experiences by individuals with disability to be the result of activity restrictions that are caused by social factors (as cited in Thomas, 2002). However, due to the offensive nature of the word “handicap” it does not aid in the re-centering of disability within a social context (Thomas, 2002). Pfeiffer (1998), suggests this displays that there was a split between the leaders in the disability community; some viewed the “handicap” category as an opportunity to collect data regarding the environment while others saw it as a revitalized eugenic campaign (as cited in Thomas, 2002). These terms were and still are considered by many to be inappropriate labels for individuals with disability, especially those who are able to participate in society with minor accommodations or adaptations within their environment. The ICIDH also did not examine the role of the environment, which is important as the environment can hinder individuals (Badley, 1995).

Among these three aforementioned models, disability was not defined in a consistent manner (Table 1). Due to these inconsistencies, when scholars and researchers alike would read and review literature on disability, it was not clear what concept or definition was being implemented. The use and availability of an internationally accepted model such as the ICF facilitates the possibility of promoting and increasing the progress of disability research

(Freedman, 2009; Jette, 2009). Thus, regardless of the flaws in the ICF, it is important that one model be used. It is significant to note that the ICF is not yet in its final form (WHO, 2003).

Table 1. The Comparison of Components of Models of Disability

Disability Models	Components of models of disability				
	Cell and/ or Tissue	Organ	Individual	Society	External Factors
Nagi, 1969	Pathology	Impairment	Functional Limitation	Disability	
ICIDH (WHO, 1980)	Disease	Impairment	Disability	Handicap	
Vergugge-Jette, 1994	Pathology	Impairment	Functional Limitation	Disability	
ICF (WHO, 2001)	Body function and Structures		Activity	Participation	Personal and Environmental Factors

In 2001, the WHO published their new and revised ICIDH and called it the ICF. The ICF maintains the goal to provide “a unified and standard language and framework” (WHO, 2001). The ICF was created based on an interactive model that did not only focus on the impairments but one that also included activity limitations and social participation. This is an important aspect, as impairments and chronic illnesses have the ability to create restrictions to activities of daily living, which constitutes disability (Thomas, 2004). The current understanding of disability, which contains both a medical and social perspective in an integrated approach, was accepted and implemented by the ICF. The ICF uses “disability” as the umbrella term under which impairments, activity limitations and participation restrictions are included (WHO, 2002). Disability is defined as “the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual

lives" (WHO, 2001). The ICF implements an approach to consider health from the perspective of the individual, social, and biological references (WHO, 2001).

The ICF model consists of two parts: part one is made up of functioning and disability, which is comprised of body function and structures, and activities and participation while part two is made up of contextual factors which includes environmental and personal factors.

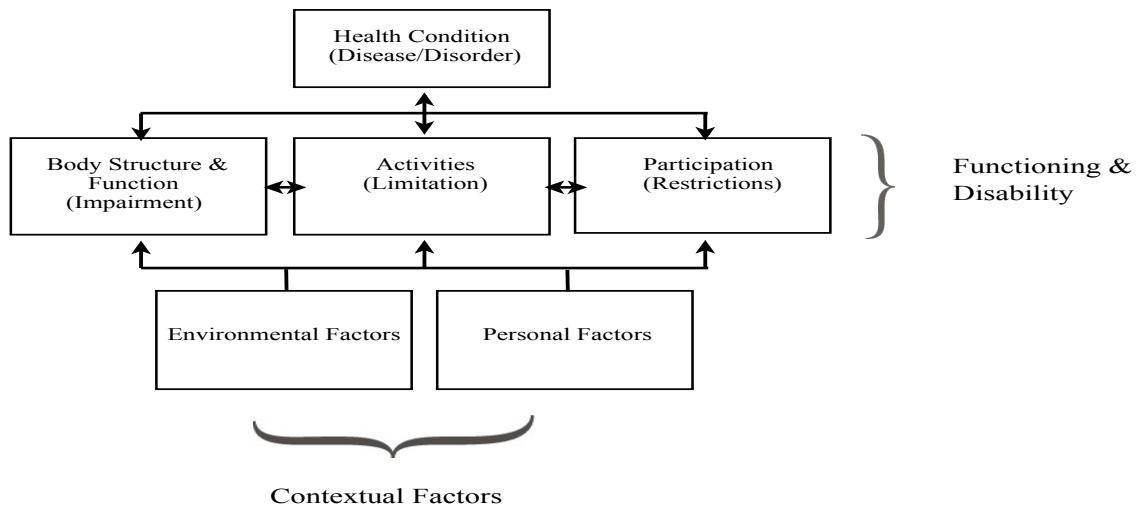


Figure 1. The ICF and the interaction of its components, adapted from the WHO (2002b).

Figure 1 displays the interaction between “health conditions” and “contextual factors” in the outcomes for disability and functioning (WHO, 2002). The “health conditions” represent medical conditions comprised of disorder, disease, and injury while the “contextual factors” encompass social influences that include personal and environmental factors.

Body functions are the psychological and physiological functions of body systems. Body structure is the anatomical parts of the body, which include the limbs, organs and their components. Activities and participation are provided in the ICF model in a list that includes a complete range of life areas including: learning, watching, employment and interpersonal

interaction. Environmental factors consist of the social, physical, and attitudinal environments in which an individual lives. Personal factors may include: age, education, experiences, gender, social background, and any other variables which may affect the individual's experience of disability (Appendix B).

The framework of the ICF provides a perspective to move beyond the debate surrounding the differences between the medical and social models of disability (Shakespeare, 2005) by providing terminology and a classification system regarding function and disability from a perspective of both the social and medical model of disability. Like any model there are flaws such as: the lack of distinct personal factors (Wade & Halligan, 2003; Jelsma, 2009, Hemmingsson & Jonsson, 2005) and nonspecific environmental factors (Whiteneck & Dijkers, 2009), the need for precise domains for activities and participation (Freedman, 2009, Badley, 2008; Wade & Halligan, 2003), and the need for a dynamic process of disability (Freedman, 2009). Although the ICF model included codes for such factors as emotional functions and pain, it was reported to be difficult to code perception of self-health (Corrigan & Bogner, 2004; Cieza & Stucki, 2005). As of 2006, when PALS 2006 was conducted, the ICF had not yet provided a classification system for personal factors, which was due to "the large social and cultural variance associated with them" (Rosenbaum & Stewart, 2004). The ICF provides a broad description: "Personal factors are the particular background of an individual's life and living, and comprised of features of the individual that are not part of health conditions or health states. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experiences, overall behaviour pattern and character style, individual psychological assets

and other characteristics, all or any of which may play a role in disability at any stage in life” (WHO, 2001). The laxity in the description provided above regarding the personal factors in the ICF supports the views of authors such as Wade and Halligan (2003), Jelsma (2009), and Hemmingsson and Jonsson (2005) that the ICF does not provide definite definitions concerning what should or should not comprise personal factors.

The definition of environmental factors in the ICF model contains the word “environment” which is the very term they are defining (WHO, 2001). Due to this, the measurement of environmental factors continues to be in both operational and conceptual confusion (Whiteneck & Dijkers, 2009). It was also determined that the environmental factors were too broad and this prevented all of its aspects from being measured simultaneously; as a result, there is a need for a theory which examines how the environment affects an individual’s functioning (Whiteneck & Dijkers, 2009). Additionally, there is a lack of validated measures for the concept of environment and its function as an influence on or determinate of behaviours (Kendig, 2003; Friedman & Wachs, 1999).

The ICF model has conceptualized participation; however, it has created confusion by failing to differentiate it sufficiently enough from activity, which is displayed by the creation of one classification scheme for both concepts (Whiteneck & Dijkers, 2009). The measurement of participation in the ICF model is also difficult since individuals have different preferences and different rates of availability in the type of participation in which they choose to be involved (Whiteneck & Dijkers, 2009).

HRQoL and the ICF represent two independent interpretations of functioning and health (Cieza & Stucki, 2005). It is common in health reporting, clinical practice and research such as the current project, that HRQoL and the ICF are used simultaneously

(Cieza & Stucki, 2005). However, during the creation of the ICF, the WHO stated that a biopsychosocial model was used to provide a clear view of disability and functioning, as well as, distinct perspectives on health from biological, social and individual perspectives (WHO, 2001). The ICF framework, having its foundations in a biopsychosocial model would then account for the individual's perception of life experiences, which is a component of QoL that is incorporated into the understanding of health and HRQoL (Huber, Sillick, & Skarakis-Doyle, 2010). Based on this ideology it was proposed that HRQoL would be best located in the personal factors component of the ICF's framework (Huber, et al., 2010). Moreover, Huber et al. (2010) switched the positioning of personal factors with environmental factors to have personal factors located on the left side of the ICF's framework, which they believe increased the perception of its importance within the contextual factors. Although by definition the personal factors are not within the health domain, the fact that they have an impact on personal health nevertheless results in their correlation to the health domain (Huber, et al., 2010).

Although stress and aging are also considered personal factors, they too are considered to impact health and are found in the definition of health conditions (Huber, et al., 2010). The WHO defines health as "a state of complete physical, mental and social well-being" (WHO, 1986) that displays the continuous flow between personal factors and functioning within health and/or the concept of health states (Huber, et al., 2010). This displays that the interaction within the personal factors component can result in different experiences of disability and thus has different outcomes on one's HRQoL (Huber, et al., 2010). Health condition refers to disease or disorder and health state refers to functioning

within a health related domain (Huber, et al., 2010). For example, an individual's health condition could be cataracts, which affects their health state in terms of their ability to see.

Figure 2 illustrates the conceptual framework used to guide this analysis.

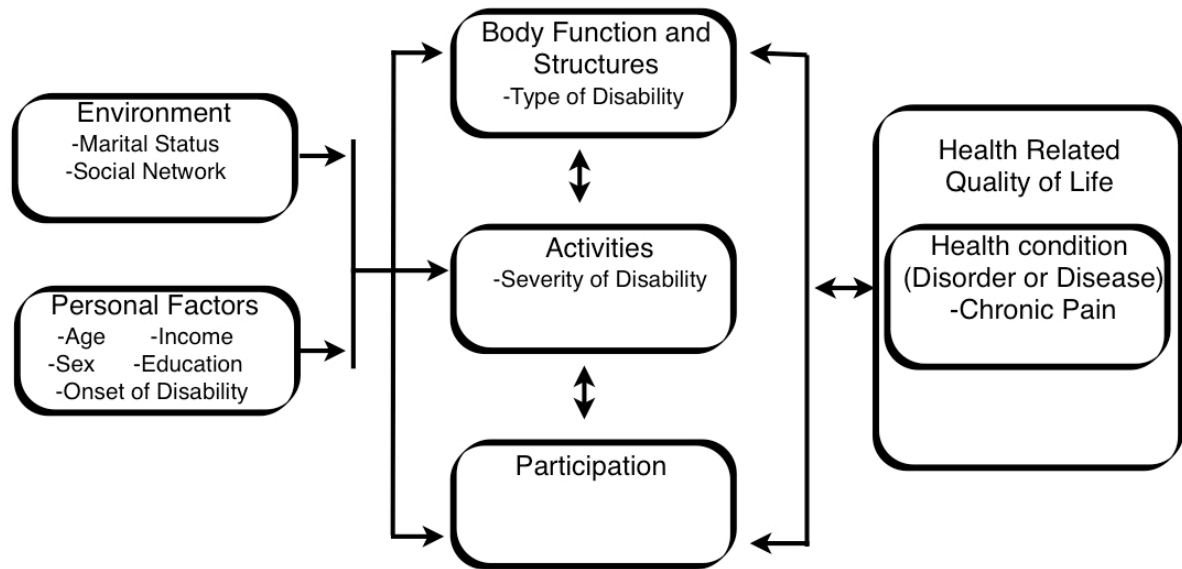


Figure 2. Conceptual Model

The ICF is the only framework that is internationally recognized which allows for consistency in reporting data (Jelsma, 2009) and is therefore critical, even with the flaws highlighted above. The ICF framework provides a theoretical basis for policy formulations, measurement, and definitions of disability (WHO, 2002).

The ICF framework was followed as model by Statistics Canada's PALS 2006 and not all of the components were implemented (MacKenzie, 2001). There were modifications made to the social model and ICF concepts for analysis in PALS 2006 and as such, disability was defined as "the relationship between body structures and functions, daily activities and social participation, while recognizing the role of environmental factors" (Statistics Canada, 2001).

The differences between the medical model of disability and the social model of disability are significant to this research. As aforementioned, the medical model views disability as a problem within the individual, which stems from the disability, versus the social model of disability, which positions the problem of disability within society (Oliver, 1996). The medical model of disability uses medicalization to understand social problems in medical terms. The social model of disability describes disabilities as the by-products of social constructs, suggesting that the current perspective of disability was created by previous ways of speaking and thinking about disability (Danforth & Rhodes, 1997). Everyday life has been influenced by the phenomenon of scientific medical language and this medicalization has slanted and reinforced the common view that disability is a problem within individuals (Conrad, 2004). The current medical practice of identifying problems within the individual has the potential to affect, persuade, and influence society's approach to thinking and speaking about individuals with disability as experiencing problems and/or non-problems when participating in daily activities. The medicalization of language places the difficulties and problems of the disability directly on the individual, as it disregards the implications and impact of the environment, policies, and attitudes toward disability and how they have the potential to contribute to the disability.

Society has come to depend on science and medicine to dictate what to do, what to eat, and fundamentally how to live our lives, which provides insight into the systemic barriers created by science and medicine toward society's view of disability. As a society we primarily go to physicians when our bodies and/or minds have a problem or condition to allow them to diagnosis it, so that it can be treated or cured in an attempt to become healthy. This ideology implies that we compare disability to ill health rather than relating disability

to living with diversity. Thus, there is a negative relationship created surrounding the term disability and those individuals who are labeled with having a disability. Furthermore, the medical professions diagnose and directly label specific types of disabilities such as “mental retardation” or “down syndrome” and by doing so they fundamentally define individuals in terms of their disability. These labels are medicalized and vague as they do not include the social dimensions which also encompass the disability. Conversely, Disability Studies would rather use language and terms that does not demean the individual, are culturally sensitive and identify the humanity of the individual prior to the disability label (Goodley & Runswick-Cole, 2011).

In PALS 2006 the language used to describe disability was to identify 10 specific types of disability, [agility, communication (speech), developmental, emotional (psychological), hearing, learning, memory, mobility, pain, and seeing, as well as, unknown]. The unknown category was created from individuals who answered “yes” to one of the questions on general limitations and “no” to the specific disability type questions classified as “nature of disability unknown” (Canada Mortgage and Housing Corporation, 2010). As PALS uses the ICF as a model but does not adhere to it 100%, it selected elements which reflected the common disabilities listed above (Stobert & MacKenzie, 2008). This use of labeling is not supported by the social model of disability and displays how PALS did not take it into consideration during its creation and implementation.

Section 3 Literature Review

This review provided a summary of the current literature on disability, chronic pain, and HRQoL among older adults. First, national disability surveys in Canada were researched. Second, the concept of aging and aging with disability were addressed along

with disability and sex/gender differences. Third, pain and chronic pain and disability were investigated, along with pain and older adults, pain and sex/gender differences. Lastly, QoL, HRQoL and its measures were explored followed by HRQoL's relationship to disability and chronic pain.

3.1 National Disability Surveys in Canada

In 1980, the Canadian federal government created a special parliamentary committee on the topic of the Disabled and Handicapped (Statistics Canada, 2001b). This committee was formed to voice the concerns and needs of Canadian persons with disabilities to the House of Commons (Statistics Canada, 2001b). In 1981, the committee published "Obstacles", which was a report of their findings that included 130 recommendations (Statistics Canada, 2001b). One of the recommendations addressed the lack of national data on Canadian persons with disabilities. Thus, Statistics Canada was provided with a direct recommendation to "give a high priority to the development and implementation of long-term strategy which will generate comprehensive data on disabled persons in Canada, using population-based survey and program data" (Canadian House of Commons, 1981). Between 1986 and 2006, the Canadian federal government created and conducted four disability specific surveys following a population census.

Based on those recommendations in 1986, Canada introduced the first series of activity limitation questions in the Census (Statistics Canada, 2006). These questions were later used to form the first post-censal disability survey known as the Health and Activity Limitations Survey (HALS), which was conducted during 1986. HALS 1986 was the first comprehensive survey conducted in Canada that focused specifically on individuals with disabilities. The target population in HALS 1986 was all individuals with a physical, sensory

or psychological disability living in Canada at the time of the 1986 Census (Statistics Canada, 1989). The 1991 Census contained the same activity limitations question as in 1986. Following the 1991 Canadian Census, HALS 1991 was conducted. Both HALS were designed to collect information regarding the life experiences of Canadian persons with disability including if and how their disabilities impacted their daily living on a cross-sectional basis.

HALS 1986 and 1991 provided a national representation of individuals with disability in Canada including individuals residing in households, as well as, individuals residing in Canadian health institutions. Both HALS provided a national representative sample of disabled Canadian children and adults. In HALS 1986 and 1991, an individual was noted to have a disability if the restriction lasted or was expected to last at least six months and was not eliminated by the use of technical aid (Statistics Canada, 1989 and Statistics Canada, 1991).

The 1996 Census contained the same Activity Limitation question; however, HALS 1996 was not conducted due to budget constraints (Blake & Keshen, 2006). Following the cancellation of the HALS, there was discussion and lobbying to bring back “a persons with disability survey” and in 2001 the Participation and Activity Limitations Survey (PALS) was introduced, which replaced HALS (Blake & Keshen, 2006).

Following a ten year hiatus from the last time data was collected on Canadian persons with disability, there was a need to make changes to the survey to better represent the reality of this population (Statistics Canada, 2001). Human Resources Social Development Canada (HRSDC) provided the funding to allow PALS 2001 and 2006 to take place (Statistics Canada, 2007). PALS and HALS both provide information regarding “the

demographic and socio-economic situation of persons with disabilities, as well as, the type and severity of their disabilities” (Statistics Canada, 2002). PALS and HALS are not comparable as the Canadian Census contained different filter questions to identify their participants. PALS 2006 sampled participants who answered positively to the disability filter questions in the Census in 2006, while HALS targeted those who also responded negatively.

The objective of PALS was to collect data regarding persons with disabilities who experienced limitations in their everyday activities due to a health related condition or problem (Statistics Canada, 2001). PALS defined disability using the WHO’s framework of disability provided by the ICF (Statistics Canada, 2001). The ICF defines disability as the relationship between the body structures and functions as well as daily activities and social participation, while recognizing the role of the environment factors (WHO, 2008). The 2011 Census still contained the two activity and limitation filter questions; however, there was no PALS 2011 data collection (Statistics Canada, 2011). PALS 2011 was eliminated by the Human Resources and Skills Development of Canada who were responsible for its funding (Clark, 2010). Having the funding removed to cover the cost of running PALS in 2011 creates a void in the Canadian collection of data for persons with disability. PALS data was a critical component to allow the governments and public alike to have access to a rich data source that produced integral information regarding Canadian persons with disability.

3.2 Aging

An aging population is not a new concept, and in Canada the population has been continuously aging; however, certain periods in time experience more expeditious aging than others. This period of expeditious aging is due to larger proportions of the population

reaching the age of 65 and over. It is predicted that by 2036, 24.5% of Canadians will be older than 65 years of age (Statistics Canada, 2010). With this increase in older adults in Canada, it is very important to have a greater understanding with regards to health problems in this specific age demographic. As well, with increased age the prevalence and the severity of disabilities increase (Williams, 2006).

Older adults are not a homogeneous group due to the differences between the young older adults, the middle older adults, and the old older adults. This is due to the aging process affecting each individual in a unique manner and is a result of several interactions taking place between: biological make up, effects of disease processes, environmental and lifestyle influences (McConnell, 1997). Individuals age at different rates as a result of biological age, social age, and psychological age which are not taken into account in one's chronological age. However, in this research, age was measured by chronological age, as it is the standard measurement in the majority of the literature. There has yet to be a single method used to categorize the subgroups of older adults. In previous research there have been several divisions of the older adult population. For instance, Field and Minkler (1988) used the following groupings: young old (60-74), old old (75-84) and very old (85 and older). Meanwhile, Given and Given (1989) used a similar grouping method: young old (65-74), old/mid old (75-84) and oldest old (85 and older). In this research, a similar method of grouping was applied: young old (55 to 64), mid old (65-74), and old old (75 and older). Starting at a younger age group for older adults with disability was important in order to take into consideration that older adults with intellectual disabilities have a shorter life expectancy (Bittles, et al., 2002; van Schrogenstein Lantman-de Valk, et al., 1997).

3.3 Aging and Disability

When examining the older adult population with disability it appears that there are two distinct groups of individuals. The first group is made up of those who have lifelong-disability or early-onset disability and are said to “age with disability” (Verbrugge & Yang, 2002). The second group of individuals is made up of those who acquired disability in mid to later life and are said to have “disability with aging” (Verbrugge & Yang, 2002). However, aging and disability overlap throughout life and there has yet to be any definitive age or stage where this takes place (Bigby, 2002). It is probable that this is due to the fact that disability and aging have been separate in the literature for many years (Anesello & Eustis, 1992; Rose & Ansello, 1988; Torres-Gil & Putnam, 1999). The majority of disability begins in old age; however, regardless of whether an individual ages with disability or has disability with aging, both continue to age with disability and disability applies regardless of the age of onset of disability (Verbrugge & Yang, 2002). Within the aging literature little distinction could be found between “age with disability” and “disability with aging”.

Disability in older adults is a frequent occurrence (Heikkinen, 2003). The most prominent risk factor for disability is chronological age (Guralnik, et al., 1993). To address for the increase in disability as the population ages, von Strauss, Agüero-Torres, Kareholt, Winbland, & Fratiglioni (2003) suggested classifying the older adult population into age groups to account for the increase in severity levels of functional capacity. Chronological age also has a significant effect on other risk factors associated with functional decline in old age, such as level of education and fatigue experienced during activities of daily living (Avlund, 2004).

Similarly to disability in the general sense, there is not a single definition used to describe older adults with disability. There are several descriptions of disability in older adults with disability. One such description is a deviation or gap between the demand necessary to complete a task and the individual's capability to complete it (Verbrugge, 1990). Another description is the inability to complete or perform certain exercises or roles, which could previously be accomplished without problems or aid from another individual (Verbrugge & Jette, 1994). This explains disability as a decline in an individual's ability over time. As an individual's ability to perform tasks decreases, adjustments can be implemented to decrease the demand of the tasks to allow older adults to maintain their independence and participate in day-to-day activities.

In Canada in 2001, it was determined that one out of every seven Canadians (14% of the Canadian population) aged fifteen and older (3.4 million people) living in private households reported having some degree of disability (Statistics Canada, 2001). Furthermore, the results from PALS 2001 verified that there is an increasing prevalence of disability in the Canadian aging population with both disability and severity of disability increasing with age; approximately 40% of older Canadian adults aged 65 years and older and 53.3% of Canadians aged 75 and older reported having a disability (Statistics Canada, 2001). PALS 2001 also found that the prevalence of most types of disabilities also increased with age, with a significant prevalence of disabilities related to agility, hearing, mobility, pain and vision (Statistics Canada, 2001). It was also found that mobility disability was the most prominent, affecting more than seven out of ten Canadians with disability (Statistics Canada, 2001). Disability affects all of Canadian society and an individual's age, ethnicity,

religion, sex and/or socioeconomic background does not increase nor decrease the occurrence of disability (Wright, 2001).

Pain has been illustrated to be independent of disability (Crombez, Vlaeyen, Heuts & Lysens, 1999); however, pain is a disability in itself and is known as pain-related disability (Turner, Jensen, Warm, & Cardenas, 2001). In Canada, there have been varying reports regarding the prevalence of chronic pain in the general population. The fluctuation has been found to be between 15% (Van Den Kerkhof, Hopman, Towheed, Anastassiades, & Goldstein, 2003) and 29% (Moulin, Clark, Speechley, & Forster, 2002). For example, in Canada, 27% of older Canadian adults living in households reported experiencing chronic pain (Ramage-Morin, 2008). As the Canadian population with disability ages, their reporting of chronic pain disability increases (Statistics Canada, 2011b). It was also found that Canadian females at any age were more likely to report a chronic pain disability when compared to their male counterparts (Table 2) (Statistics Canada, 2011b).

Table 2. Characteristics of Chronic Pain, by Sex.

Age	Male % (n)	Female % (n)
15 to 19	1.6% (17,770)	2.5% (25,560)
20 to 24	2.3% (23,710)	3.1% (31,030)
25 to 54	7.3% (486,550)	8.9% (621,080)
55 to 64	15.2% (269,660)	19.2% (354,530)
65 to 74	20.6% (219,270)	24.8% (219,690)
75 +	28.8% (211,690)	38.5% (413, 120)

3.4 Disability and Sex/Gender Differences

The terms sex and gender have two different meanings according to the WHO (2011). The term sex is defined as “the biological and physiological characteristics that define men and women” (WHO, 2011) versus the term gender which refers to “the socially constructed roles, behaviours, activities and attributes that a given society considers

appropriate for men and women” (WHO, 2011). Even though the WHO provides a concrete definition regarding the use of both of these terms, the actual utilization of these terms remains uncertain. Following a literature review conducted by Torgrimson and Minson (2005) that examined the use of sex and gender in scholarly journals, it was found that scholars appropriated the word gender as a politically correct manner to discuss sex in their publications. Due to this discrepancy in the literature and the personal choice exerted by the authors, sex and gender was not distinguished in this literature review, and the terms will be used interchangeably.

Disability and sex/gender affect each other in various ways. In the older adult population the prevalence of disability is considerably higher among females than males. In Canada, it was found that in 2001 disability rates were higher among females than males (Statistics Canada, 2001). In 2001, among individuals between 25 and 44 years of age, 7.7% of males reported disability compared to 8.3% of females who reported disability, among those 45 to 64 years of age, 17.3% of males reported disability compared to 19.3% of females, among those between 65 and 74 years of age, 32.5% of males reported disability compared to 33.5% of females reporting disability and finally among those aged 75 and older, 54% of males reported disability compared to 57.8% of females who reported disability (Statistics Canada, 2007b) (Appendix C).

Throughout the literature there have been several factors to explain this trend. One factor is gender differences in morbidity patterns; females are more likely to experience disabling diseases, which are nonfatal such as osteoarthritis while their male counterparts more commonly experienced suffering from fatal short-term conditions such as cardiac arrest (Ettinger, et al., 1994). Females on average tend to have a longer life expectancy than

males; therefore, females will spend more time having a disability than males. As well, females have a higher incidence rate of disability than their male counterparts (Leveille, Penninx, Melzer, Izmirlian, & Guralnik, 2000).

3.5 Social Network and Disability

Social well being is important to aging with or without disability. Social engagement provides an individual with psychological resources, which are needed to aid their ability to become flexible to live. This is especially significant for an individual with disability. In a study performed to examine the degree by which social engagement was associated with reducing the risk of task-specific disability among older adults 65 years of age and older, it was found that those with frequent social engagements reported less physical disabilities (Mendes de Leon, Glass, & Berkman, 2003). It has been found that maintaining high levels of social participation throughout one's life has the ability to provide an individual with psychological resources such as sense of purpose and control over one's life which are needed to aid in their ability to become flexible to live with disability (Diehl, 1998; Mendes de Leon, Glass, & Berkman, 2003; Mendes de Leon, Seeman, Ruchardson, & Tinetti, 1996; Peat, Thomas, Handy, & Croft, 2004). Social participation does not prevent or delay disability; however, the individual's psychological resources from social participation can aid in minimizing the impact of disability and allow for successful aging. Individuals with disability living in the community are 50% more likely to live alone than their non-disabled counterparts (Kaye, 1998). This suggests that individuals who are disabled have less opportunity for social participation. It is also possible that they experience lower income as well as poorer exercise and diet patterns in part due to this solidarity (Seeman, 2000).

3.6 Pain

Pain is an “unpleasant sensory and emotional experience associated with actual or potential tissue damage, or is described in terms of such damage” (International Association for Study of Pain, 1979). “The person with pain is the only authority about the existence and nature of that pain, since the sensation can only be felt by the person who has it” (McCaffery & Beebe, 1994). Therefore, there are several aspects of pain such as the presence of pain being caused by actual or potential tissue damage. The experience of pain is a subjective experience with a complex response (Von Korff & Le Resche, 2005). Therefore, if one stimulus is presented differently, individuals may react in different ways; or the same individuals may react differently in different situations or at different moments (Pigeon, McGrath, Lawrence, & MacMurray, 1989).

There are two different types of pain: acute and chronic (Wall & Melzack, 1999). Pain is considered acute when it is associated with unpleasant perceptions and emotions, in addition to, psychological and behavioural reactions and autonomic reflex responses within a well defined time pattern with signs of hyperactivity in the autonomic nervous system (ANS) (Bonica, 1987; Gibson, Katz, Corran, Farrell, & Helme, 1994; Hawthorn & Redmond, 1999). Hyperactivity in the ANS can include sweating/perspiration and vasodilation; however, these signs are not always apparent in the older adult population (Gibson et al., 1994). Pain is defined as chronic when it lasts a month beyond the normal course of healing for disease/injury or when it is present for 3 to 6 months (Bonica, 1987). Chronic pain differs from acute pain as chronic pain is often more difficult to diagnose and treat as it has the ability to cause changes in the central nervous system (CNS) (Hawthorn & Redmond, 1999).

The traditional definition used to describe chronic pain relies solely on the duration of the pain (Merskey & Bogduk, 1994). However, using this duration-based approach to define chronic pain raises concern, as it is not inclusive of the perspective that chronic pain is multidimensional (Turk & Rudy, 1988). There is an alternative approach to describe chronic pain rather than the duration-based approach. This other perspective includes a combination of pain related information such as severity, duration, and prognostic variables (Von Korff, 1992). PALS 2006 implemented a combination approach to defining chronic pain when, in the filter section, all participants were asked a series of seven pain related questions. These questions were then used to create the derived pain related variable, which takes into account the perspective that chronic pain is multidimensional, set forth by Turk and Rudy (1988).

3.7 Physiology of Pain

The Gate Control Theory was developed to describe the mechanisms of pain and the understanding of pain (Melzack & Wall, 1965). This theory proposed that there is a neuronal mechanism located in the dorsal horn of the spinal cord, which acts as a gate mechanism through which peripheral information passes (Melzack & Wall, 1965). The Gate Control Theory was the first theory to present pain perception as a dynamic process of the brain (Melzack, 1993). Usually, cellular damage has transpired in order for us to perceive pain; however, psychological factors have been found as contributors to pain processing as well (Sullivan, et al, 2001). As a result of tissue damage, complement activation takes place which leads to the release of complement fragments that activate local mast cells leading to the release of leukotrienes, prostaglandins and histamine. Prostaglandins cause dilatation in the blood vessels, which increase the effects on histamine and bradykinin (Eales, 2003). As

well, the release of prostaglandin increases the sensitivity of pain receptors (Clancy & McVicar, 1992). Histamine and bradykinin then combine to nociceptors (pain receptors) and initiate the neural transmission associated with pain perception in the dorsal horn of the spinal cord.

There are two types of pain neurons: A-delta fibers, which are thinly myelinated, fast pain fibers and C-fibers, which are non-myelinated, slow pain fibers (Clancy & McVicar, 1992). In the majority of tissues in the body there is a network of A-delta fibers and C-fibers. These fibers have different functions to different nociceptive stimuli. C-fibers are activated by dull aching pain and pain which is poorly localized, while A-delta fibers give rise to the first localization of sharp pain. The nociceptive stimulation from the A-delta fibers and C-fibers travel from the activated tissue down to the spinal cord into the dorsal horn. In the dorsal horn, also known as the “gate” there are other nerve cells that provide sensory input information (Melzack & Wall, 1965). If there is simultaneous information reaching the dorsal horn from a nociceptive and non-nociceptive fiber, the nociceptive input can be moderated by the non- nociceptive input (Melzack & Wall, 1965).

Since the Gate Control Theory was first introduced in 1965 it has undergone revisions to develop the neuromatrix theory of pain (Melzack, 1999). The neuromatrix theory of pain uses a broader perspective to examine pain and it proposes that pain is a multidimensional experience that is produced not only from tissue damage but also from areas of the brain. Therefore, the brain has the ability to generate perceptual experiences even without external input (Melzack, 1999). The brain is composed of neural networks for perceiving the body parts, therefore, the brain does not passively receive input from the body but it generates the experiences of the body and sensory input merely regulates the experience and does not

directly cause it (Melzack, 1993). The input of nociceptive information leaves the dorsal horn and runs through the nerve pathways to the thalamus through to the sensory cortex where memory of previous pain experience, knowledge, and cultural influences exert their effects on the perception of pain.

3.8 Chronic Pain and Disability

Almost each and every one of us has experienced acute and non-chronic pain at one time or another. Pain commands our attention and our primary focus becomes how to alleviate the sensation of pain. However, this is very different among individuals who are living with prolonged and/or recurring pain commonly known as chronic pain. Some use the term “making friends” with it as the way to regain control of one’s life and general enjoyment (Wendell, 1996).

Chronic pain has the potential to affect up to 80% of the population at some point in their lives (Waddell, 1992). The presence of disability has the potential to be associated with being in pain, however pain and disability do not automatically co-occur (Turner et al., 2004; Turk, 2002). The literature finds the co-variation between disability and pain intensity to be a moderate to weak relationship (Crombez, et al., 1999; Geisser, Robinson, Miller, & Bade, 2003; Gronblad et al., 1993; Gronblad, Hurri, & Kouri, 1997). However the research published by Peters, Vlaeyen and Weber (2004) found that pain intensity provided the strongest predictor of disability. The use of self-identification and personal rating of disability has been found to be a significant predictor of chronic pain intensity (Epping-Jordan et al., 1998).

Pain, which results in disability, can be defined as “the extent to which chronic pain interferes with a person’s ability to engage in various life activities” (Pollard, 1984, p.974).

The interference involves interaction between variables such as: extent and duration of pain (Tait, Pollard, Margolis, Duckro, & Krause, 1987), and the severity of pain (Von Korff, Dworkin, & Le Resche, 1990).

Pain is a subjective experience and disability is one of the products of that experience. Today's society continues to have a perspective that impairments and pain must be avoided and has yet to develop a level of comfort (Wendell, 1996). Oliver (1996) purposes that individuals only have the ability to speak of their own experiences of impairment and what is painful to one individual may be of a lesser degree for another (as cited in Wendell, 1996). However, Matthews (1983) suggests the interest in these subjective experiences is rare, the focal interest is about medical diagnoses and physical appearance (as cited in Wendell, 1996). Individuals with disabilities, like everyone else, are subjected to the cultural pressures such as to deny bodily weakness which then forces individuals to attempt to have the perfect body; however, most individuals with disabilities cannot even attempt to have their bodies fit into these societal models (Wendell, 1996).

Chronic pain-related disability was first proposed by Fordyce (1976) and Fordyce, Shelton, and Dundore (1982). It was theorized that chronic pain-related disability could be explained by behavioural conditioning, negative reinforcement (avoidance of activity which causes pain) and positive reinforcement (increased attention specifically from a loved one) as a contributor to the extended role of being sick from those experiencing chronic pain (Fordyce, 1976; Fordyce, Shelton, & Dundore, 1982). In addition, it was determined that cognitive factors may also have the potential to predispose an individual to react to pain with fear and therefore increase their sensitivity to nociceptive information (Turk, Meichenbaum, & Genest, 1983). Those living with chronic pain disabilities have described

them as a radio which is constantly playing, but whose volume changes a great deal (Wendell, 1996). Someone with a chronic pain disability must make a conscious effort to remind himself or herself that unlike a “healthy” individual experiencing pain, their pain is not a warning system for the body and their pain is meaningless (Wendell, 1996).

A vast amount of literature is available regarding the effects of chronic pain on the general population as well as, older adults. In contrast, there is very little literature examining how chronic pain affects individuals with disability. Gatchel and Turk (1999) suggested that those individuals with disability are possibly at greater risk for experiencing chronic pain. The available literature regarding individuals with disability has examined a homogenous sample of specific impairments and disability that includes: spinal cord injury (SCI), cerebral palsy (CP), pervasive developmental disorders, psychological disabilities, learning disabilities, memory disabilities (traumatic brain injury and Alzheimer’s disease), and seeing disabilities (cataracts).

Several authors have found that among the SCI population there is a high presence of chronic pain (Dalyan, Cardenas & Gerard, 1999; Jensen, Hoffman, & Cardenas, 2005; Budh, et. al, 2003). It is significant to note that between studies, pain was measured differently and the location of pain occurred at the site of injury, above the injury and/or below the injury location. Dalyan and colleagues (1999) found that the occurrence of pain was prevalent in the shoulder (71%), wrist (53%), hand (43%) and elbow (35%). Pain was also found to be associated with functional activities such as: sleeping or at bedtime (21.1%), pressure relief (19.6%) and wheelchair sports (16.1%) (Daylan, et al., 1999). Turner, Cardenas, Warms and McClellan (2001) found in their study that 71% of participants with SCI reported high levels of pain intensity and 36% rated their chronic pain

as severe. It was found that individuals with SCI frequently reported more than one pain problem (Turner, et al., 2001).

Cerebral palsy is commonly related to a childhood disability (Kuban & Leviton, 1994), although people with this disability age past childhood. Schwartz, Engel, and Jensen (1999) found that 67% of males and females with CP reported chronic pain. Turk, Geremski, Rosenbaum, and Weber (1997) examined females with CP and found that 84% reported chronic pain and 56% reported that pain limited the activities in which they participated. It is important to note that among the general population it has been found that females often report higher rates of chronic pain than do their male counterparts. These sex differences may describe the variation in the proportion of reported chronic pain of those with CP between Schwartz, et al. (1999) and Turk and colleagues' (1997) research.

Developmental disabilities such as Autism and Down Syndrome have been linked to experiences of chronic pain and individuals with these disabilities often have a difficult time regulating and reducing the pain signal (Bursch & Zeltzer, 2002). It has also been found that individuals with developmental disabilities have difficulties with communication (verbal or non-verbal). It is difficult for individuals with developmental disabilities, especially children to have the vocabulary to accurately explain their sensory experience (Bursch & Zeltzer, 2002). Among individuals with developmental disabilities who are not verbal, it has been found that they may express chronic pain by decreasing their activity and may become more withdrawn and subdued (Chambers, Reid, McGrath, & Finley, 1996; McGrath, Romus, Camfield, Campbell, & Hennigar, 1998). Bursch and Zeltzer (2002) suggested that due to the differences in sensory processing among individuals with developmental disabilities, it

could be postulated that individuals with developmental disabilities experience chronic pain at higher rates.

Chronic pain is regularly associated with and accompanied by psychological disabilities, which also raises concerns due to the difficulty in separating these comorbid conditions (Mayou, Kirmayer, Kroenke, & Sharpe, 2005). Such psychological disabilities are high levels of anxiety associated with avoidance and fear, which have been identified, in chronic pain (Asmundson & Taylor, 1996). A review of the literature suggests that the prevalence of chronic pain among those who have depression varies between 10%-100% (Romano & Turner, 1985).

A review of the literature was not able to find any studies which examined the relationship between chronic pain and the following types of specific learning disabilities: dyslexia, dysgraphia, and dyscalculia in addition to the keyword “learning disability”. This is an area that requires further research.

The relationship between traumatic brain injury and chronic pain is well documented. Its presence has been known since World War I when troops were returning with what was described as “shell shock” (Myers, 1915). It has been found that the most common type of chronic pain among individuals with traumatic brain injury was chronic headaches (eg. Lahz & Bryant, 1996; Mooney, Speed, & Sheppard, 2005). Lahz and Bryant (1996) found a prevalence of chronic pain to be present among individuals with mild (58%) and moderate/severe (52%) traumatic brain injury. Mooney, et al. (2005), found that 72% of their participants reported headaches and 64% reported pain elsewhere. The relationship between chronic pain and Alzheimer’s disease is not well understood as it is postulated that their experiences of chronic pain may be altered while the perception of acute pain is intact

(Pickering, Jourdan, & Dubray, 2006). Ramage-Morin (2008), found that 36% of males and 42% of females with Alzheimer's disease residing in institutions reported chronic pain. The literature has suggested that it is possible that changes in pain experiences depend on the particular neuropathology that is being affected by the dementia or Alzheimer's disease. Research conducted by Scherder, Sergeant and Swaab (2003) found that those individuals with frontotemporal dementia and Alzheimer's disease provided indications of experiencing a decline in the affected area of pain; however, the opposite was observed among individuals with vascular dementia.

There has been a relationship found between cataracts and chronic pain among older Canadian adults (Ramage-Morin, 2008). Ramage-Morin (2008) found that among those who lived in institutions, 22% of males and 34% of females reported chronic pain and cataracts and among those older adults residing in the community, 19% of males and 25% of females reported chronic pain.

The aforementioned research indicates that chronic pain is a concern for many individuals with disability; however, it also displays the necessity to analyze a larger scope of disabilities in relation to chronic pain.

3.9 Pain and Older Adults

The prevalence and the degree of pain as one ages differs between studies (Harkins & Price, 1992; Gagliese & Melzack, 1997; Elliott, et al., 1999; Blyth, et al., 2001; Helme & Gibson, 2001). Ramage-Morin, a Canadian, (2008) found (n=39,692; age 18-85 and above) minimal increase with age from 65 to 75 and no increase in pain from 75 and older. It is significant to note that this study by Ramage-Morin (2008) used data from two population surveys in Canada, the National Population Health Survey and the Canadian Community

Health Survey, to describe the prevalence of chronic pain and to determine if chronic pain was associated with unhappiness. Brattberg, Thorslund, and Wikman (1989) (n=1009; age 18-84) found a slight decrease in pain after the age of 65. Brochet and colleagues (1998) found (n=714) that among individuals 65 years and older the prevalence of pain increased with age, and this trend was especially prominent among females. A possible explanation for these differences is the use of different research designs, methods and ways of measuring pain. Another explanation could be that older adults did not report the full range of their pain and that some may view pain as part of the normal aging process, which could lead to an underreporting of chronic pain. A further possible explanation could be the increased occurrence of chronic conditions such as musculoskeletal, respiratory, and cardiovascular disease which cause changes in the ANS and result in symptoms of pain to decrease over time (Feldt, Ryden, & Miles, 1998; Hawthorn & Redmond, 1999).

Many studies illustrate that chronic pain is common among older adults (Brattberg, et al., 1996; Brochet, et al., 1998; Helme & Gibson; 2001). In a review of the studies focusing on older adults and the prevalence of pain, the pain ranged from 20-77% among those aged 55-64, 25-80% among those 65-74 years of age, 29-86% among those age 75-84 years, and 40-79% among those aged 85 and above (Helme & Gibson, 2001). Mobily, Herr, Clark and Wallace (1994) found (n=3097; age 65+) that 86% reported some type of pain for at least a one-year duration. A study (n=143) in Winnipeg, Manitoba, Canada reported a prevalence of pain in approximately 70% of individuals aged 60 and older (Roy & Thomas, 1987). As a result of these inconsistencies in the literature regarding pain sensitivity, one cannot conclusively find a trend (Harkins, Price, & Martinelli, 1986). However, pain is common among older adults and thus, there must be a greater focus in the care of older adults to

allow sanctions to relieve the experience of pain and improve their HRQoL. It is important to note that in the literature the term pain sometimes has referred to chronic pain; therefore, to accurately reflect previous work there will be occasional use of the terms pain and chronic pain interchangeably throughout the research.

3.10 Pain and Sex/Gender Differences

Most studies have demonstrated that females have a significantly higher prevalence of pain when compared to their male counterparts (Bassols, Bosch, Campillo, Canellas, & Banos, 1999; Grimby, et al., 1999; Sternbach, 1986; Crooks, Rideout, & Browne, 1984), although there has been some deviation (Andrersson, Ejlertsson, Leden, & Rosenberg, 1993; Brattberg, Thorslund, & Wikman, 1989). It has been postulated that there are gender/sex differences in the experience of pain and that it is most likely due to biological and psychological components and their interaction (Unruh, 1996). Other studies have suggested that the difference in the experience of pain within the genders/sexes is caused by social, psychological and physiological contexts (Unruh, 1996). For example, the physiological differences have included a lower feminine pain reflex in the CNS and throughout the muscles of the neck (Komiyama, Wang, Svensson, Arendent-Nielsen, & De Laat, 2005; Lee, Lee, Kim, Kim, & Chung, 1994). A social difference example of gender/sex differences in the experience of pain could be due to the manner in which men and women are socialized and are taught how to respond to emotion; moreover, the differences in the expectation of their social roles may provide an explanation as to why more women experience chronic pain conditions (Fillingim, 2000; Unruh, 1996). Helme and Gibson (1991) suggested that males might have a decreased likelihood of reporting pain; as they feel

it is necessary to maintain the stereotype created by society that males do not show pain as that makes them appear weak.

3.11 Quality of Life

QoL has been identified as a relevant issue for health care; however, there has yet to be a consensus on how to define QoL (Bowling, 1997). QoL is a complicated concept as each individual at a certain time in space values different things (Farquhar, 1995). The concept of QoL is not new as there are references to QoL that date back to Ancient Greece (McCorkle & Cooley, 1998). The idea of QoL is found in work by Aristotle (384-322BC) where he refers to “the good life” or “doing well” to mean similar things as being “happy” (Fayers & Machin, 2007). During the majority of the twentieth century the term QoL was found in the medical field and was first connected to the eugenics movement (Koch, 2000). Later this changed and QoL focused on the potential value and good of humans.

The concept of QoL has gained more significance and importance in research. The WHO defines QoL as “individuals’ perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1998). The WHO provides a broad view, with a focus on the individual’s evaluation of QoL in a cultural, environmental, and social context. The WHO introduced the concept of QoL into healthcare and defined it as a state of physical, mental, and social well being and not merely the absence of disease or infirmity (Cooley, 1998). Therefore, the WHO highlights that there is an interaction taking place between the individual’s mental state, health, relationships, and their environment. QoL has also been defined as a subjective and elusive multidimensional phenomenon, which can explain interactions by internal perceptions/experiences and external conditions in a person’s life

(Browne et al, 1994). QoL can also be broadly defined as the complete experience of satisfaction with life (Fayers & Machin, 2000). QoL can also have a narrow focus such as: life satisfaction (George & Bearon, 1980; Sherwood, Ruchlin, Sherwood, & Morris, 1997), social support (Haug & Folmar, 1986), physical function and health (Mendola & Pelligrini, 1979; Patterson, 1975), and environmental conditions (Lawton, 1997). QoL has been defined as an outcome variable to measure an individual's illness and/or disease type (Rapp, Feldman, Exum, Fleischer, & Reboussin 1999; Raimer, 2000). There has been clarification regarding QoL within the medical context and it is more specifically known as HRQoL (Farquhar, 1995; Bowling, 1997). It is important to note that the literature has not always made the distinction between HRQoL and QoL. Therefore, to accurately reflect previous work there will be occasional reference to the term QoL throughout the research.

3.12 Health Related Quality of Life

In 1990, the term HRQoL was coined (Aaronson, 1990). HRQoL is taken from the WHO definition (WHO, 1998) and is assessed by physical, mental and social functions. HRQoL is not yet clearly and concisely defined as there are questions regarding which aspects should and should not be included (Fayers & Machin, 2000). Within the literature a number of terms have been used interchangeably such as: HRQoL, functional status, health status, and QoL (Varni, Limbers, & Burwinkle, 2007; Revicki, et al., 2000; Bradley, 2001). Although the definitions of QoL and HRQoL focus on different aspects of an individual's life, these terms are occasionally used interchangeably within the literature (Varni, et al., 2007). Within the literature relating to QoL, it has been found that authors define their variable as QoL; however, since their variable only focuses on one or two components of quality of life, their terminology of QoL provides the reader with an unclear description

(Farquhar, 1995b). An example of this is provided by Farquhar (1995b) in the Cox, Fitzpatrick, Fletcher, Gore, Spiegelhalter and Jones (1992) study, where they defined QoL in functional and health status terms, whereas using the label of HRQoL would have been more descriptive than QoL. HRQoL has been defined as the individual's overall QoL that is primarily affected by that individual's perception of his/her health (Juniper, 1997). HRQoL implements a narrow focus on aspects of life that correspond to health status and does not take into account other aspects such as the environment and one's income (Achat et al., 1998). The terminology of HRQoL is used rather than QoL to explicitly describe the dimension of health that is examined (Farquhar, 1995b).

3.13 Health Related Quality of Life Measurements

The most commonly used general measure of an individual's HRQoL is the Short Form health survey (SF-36) (Dworkin, et al., 2005). The SF-36 is an instrument that was created for assessing health status in the Medical Outcomes Study (MOS) (Ware & Sherbourne, 1992). The MOS was carried out over two-years using an observational investigation design to monitor if differences among health practitioners and in health care influenced the patients outcomes; additionally, it was used for the development and improvement of practical instruments to assess patient outcomes (Tarlov, Ware, Greenfield, Nelson, Parrin & Zubkoff, 1989). The SF-36 provides measurements of physical and mental health (Lerner, Easterbrooks & Mistry, 2003). The SF-36 is made up of a 36-item scale allocated in eight dimensions of health and well being: four represent measures of physical health (physical functioning, role limitations because of physical health problems, bodily pain, social functioning) and four represent mental health (general mental health, role limitations because of emotional problems, vitality, general health perceptions). Higher

scores of the items reflects better health and the scores in each scale are coded, summed and converted into a scale ranging from 0 (worst possible health state) to 100 (best possible health state) according to specific score algorithms. The SF-36 provides scoring algorithms to create a summary of scores from the two sub scales into 2 summary scores: the mental component summary (MCS) and the physical component summary (PCS) (Rezia, Cote, Cassidy & Carroll, 2009).

Examining HRQoL in the literature has been done using several methods: a multiple item approach and a single item approach and each have their own strengths and weaknesses (Fayers & Machin, 2007; Sloan et al., 2002). Using a single item in a questionnaire to measure HRQoL is supported in the literature for several reasons. HRQoL has the fundamental aspect to evaluate an individual's perception of their feelings regarding their own health (Gill & Feinstein, 1994). The implementation of one question allows the individual to combine various individual aspects/experiences/thoughts of their own health and come to a very personalized answer to the HRQoL question. Single item indicators have been found to be easier to administer and less stressful for the participants (de Boer, et al., 2004; Fayers & Sprangers, 2002; Sloan et al., 2002), while multi-item questionnaires have been found to be more difficult (Buck, Jacoby, Massey & Ford, 2000; Sloan et al., 2002). HRQoL is multidimensional and incorporates components of functional well being (taking part in day to day activities in and out of the home), emotional well being (social support and family support), and physical well being (symptoms and treatment side effects) (Wiklund, 1990; Cella, 1992). The use of the SF-36 among individuals with disability has raised concerns. History has illustrated that disability was commonly related to poor health and the measures of HRQoL could negate measurements of the SF-36 especially the PCS

(Krahn et al., 2009). The PCS in the SF-36 asks questions regarding agility and mobility such as climbing a flight of stairs and bending/kneeling (Krahn, et al., 2009). An individual with a mobility or agility disability would probably respond “no” to many of these questions in this domain and therefore the results would display a lower health status. Due to this reasoning and the fact that the SF-36 was not included in PALS 2006 data, this research has chosen to use a single item HRQoL question from PALS 2006 to best reflect HRQoL among Canadians with disability.

3.14 Disability and Health Related Quality of Life

Researchers have identified a ‘disability paradox’; individuals with disability or chronically limiting conditions frequently report a positive QoL (Albrecht & Devlieger, 1999). Therefore, individuals who have health and or function problems do not necessarily report a QoL score that corresponds to their health status. The results from Albrecht and Devlieger’s (1999) (n=153) study revealed that approximately half of the individuals with moderate to severe disability reported having good to excellent QoL, regardless of experiencing difficulties while performing daily tasks. The results of this research is supported in the literature as it has been found that individual’s whose QoL was being judged from external observations and rated as poor was not perceived in the same manner by the individual who was living it (Jonson Siegler, & Winslade, 1982; Cella, 1992). The individual judging another individual’s QoL tended to reflect his or her own concerns, fears, and prejudice (Jonson et al., 1982). Typically when an individual with a disability reports a lower QoL it may not be a result of the disability or chronic condition; however, it is possible that the cause might be due to the individual being a victim of social stigma (Powell & Lowenstein, 1996).

Poljicanin et al. (2010) studied HRQoL among individuals with diabetes or hypertension and also measured the effects of cardiovascular comorbidities (n=9,070) and found that individuals with hypertension and those with diabetes had lower HRQoL on all dimension of the SF-36 when compared to the healthy population. Moreover, if the individual had cardiovascular disease along with either diabetes or hypertension they reported even lower HRQoL (Poljicanin, et al., 2010). Interestingly females with diabetes reported more bodily pain when compared to those females with hypertension (Poljicanin, et al., 2010). Bengefors and Isacson (2004) found that in men, headaches affected the PCS HRQoL as measured in SF-36 and that headaches affected the psychological dimensions in women and resulted in both sexes reporting a lower HRQoL as measured in the SF-36.

Chia et al. (2007) (n=2431) found that bilateral hearing impairment was associated with poorer HRQoL scores on the SF-36 and increasingly poorer scores were associated with more severe levels of hearing impairment. Chia, Mitchell, Rochtchina, Foran, and Wang (2003) (n=3108) researched to determine if unilateral visual impairment such as cataracts had an impact on HRQoL and found that non-correctable moderate to severe unilateral impairment was associated with poorer HRQoL from the data collected from the SF-36.

There was little literature available examining HRQoL and learning disabilities; however, in one study by Davis, Nida, Zlomke and Nebel-Schwarlm (2009) which focused on post-secondary adults (n=68), it was found that students with learning disabilities reported that their emotional well-being was significantly more impaired than that of the control group and therefore, had a lower HRQoL. Arnold, Witzeman, Swank, McElroy, and Keck (2000) compared and assessed HRQoL in patients with bipolar disorder (n=44),

chronic back pain (n=30) and a control group (n=2474). HRQoL as measured by the SF-36 was considerably lower among individuals with bipolar disorder when compared to the general population and those with back pain (Arnold, et al., 2000).

The literature provides a focus on children and adolescents concerning mobility disability and HRQoL. It has been found that when cerebral palsy is present QoL reduction is proportional to the severity of the cerebral palsy (Vargus-Adams, 2005). It has been found that when spina bifida is present the neurologic-neirophysiologic measurements and QoL are highly correlated (Padua, Rendeli, Ausili, Aprile, Caliandro, & et al., 2004). As QoL is based on each individual's personal judgments and beliefs, QoL has very different meanings to different people. When an individual with any disability is prevented from attaining what is significant to that individual their QoL can be decreased.

The severity of disability experienced by an individual and the emotions that the individual has infused into that function or activity also has a significant effect (Xavier, Ferraz, Marc, Escosteguy, & Moriguchi, 2003). The occurrence of social disability that inhibits one's ability to participate in activities or tasks of daily living negatively influences one's perception of QoL or HRQoL and causes it to decrease (von Faber et al., 2001).

It is significant to note that within the disability community it is preferred that another measurement tool would have been used that incorporated intra-personal and environmental variables rather than QoL and HRQoL when assessing healthcare outcomes (Hahn, 2002). However, it was found that the use of QoL allowed medical professionals a more direct measurement of an individual's functioning to clinical evaluations (Hahn, 2002).

The review of the literature did not reveal any research, which focused on the experience of older adults. Following a review of the available literature regarding

disabilities associated with agility, developmental, memory and speech there were no studies, which addressed HRQoL in these, sub populations.

3.15 Chronic Pain and Health Related Quality of Life

Irrespective of the cause of an individual's pain, the dimensions of pain and HRQoL merge (Portenoy, 1990) causing a negative relationship to be formed between the intensity of the pain and HRQoL (Wang et al., 1999). Individuals having moderate or severe pain were found to have lower HRQoL when compared to individuals who were experiencing mild or no pain (Wang et al, 1999). In the older adult population, pain was found to be one of the most common conditions (Jakobsson, Klevsgard, Westergren, & Hallberg, 2003). The presence of pain in the older adult population affects an estimated prevalence ranging from 25% to 88% (Helme & Gibson, 2001). In the older adult population the relationship between pain, function limitations, and QoL have all been a focus of previous research (Closs, 2005; Jakobsson, et al., 2003; Reyes-Gibby, et al., 2002; Scudds & Robertson, 1998; Ross & Crook, 1998). In Canada, Ross and Crook (1998) found that there was no association between pain and measures of disability; however, it was found that individuals with pain when compared to those without pain had less satisfaction with life. It was found that participants reporting musculoskeletal pain were much more likely to have functional limitations (Scudds & Robertson, 1998). Pain and functional limitations were found to predict low self rated health in the older adult population (Reyes-Gibby, Aday, & Cleeland, 2002). Therefore, it is clear that pain has an effect on an individual's HRQoL.

The presence of chronic pain has been found to be associated with low levels of HRQoL (Picavet & Hoeymans, 2004; Kim et al., 2005; Lamé, Peters, Vlaeyen, Kleef & Patijn, 2005). As well, a dose-response was reported to have found that as pain frequency

increases the individual's self rated health decreases (Mantyselka, Turunen, Ahonen, & Kumpusalo, 2003).

3.16 Summary

The review of the literature illustrates that chronic pain is common among the older adult population and that it is known to decrease HRQoL. With the Canadian population aging, it is important that there is a greater understanding of health conditions, the presence of disability and the effects of their interrelationship in this population. There is the potential that the presence of disability may be associated with specific health conditions such as chronic pain, although pain does not always co-vary disability. As well, usually when an individual with a disability reports a low QoL it is not always a result of the disability; however, it is possible that this lower QoL is caused by the individual being a victim of social stigma. Despite this, studies focusing on chronic pain and HRQoL among older adults with disability are limited. The presence of chronic pain has been associated with lower levels of HRQoL; however, it is not known how this relationship affects older adults with disability. Further Canadian research is needed to fully assess the magnitude and scope of this relationship.

Section 4 Methodology

4.1 Study Design

This research is a secondary analysis of data from the 2006 PALS adult (ages 15 and above) master file, which also included select variables from the 2006 Canadian Census. Funding for PALS 2006 was provided by Human Resources and Social Development Canada (HRSDC) (Statistics Canada, 2007b). Statistics Canada identifies PALS 2006 as a 'post-censal' survey, indicating that PALS 2006 was conducted in both English and French

following the Canadian Census 2006. PALS 2006 is defined as post-censal because it used the 2006 Canadian Census as a sampling frame to identify its target population. The implementation of a post-censal survey has several advantages. It has the ability to be efficient in the means of collecting data on a portion of the Canadian population, which is significantly geographically dispersed. In addition, it decreases the overall respondent burden and is a cost-effective means of collecting data (Statistics Canada (2001b)).

PALS data is accessed through the Manitoba Research Data Centre (RDC) and can be analyzed using Statistical Package for Social Sciences (SPSS) version 17 and SUDAAN version 10.

4.2 Data Source

PALS 2006 consisted of a sample of adults and children residing in private and some collective households in the ten provinces, three territories and aboriginal communities in Canada. The objective of PALS 2006 was to collect information on Canadian adults and children with disabilities whose everyday activities were limited due to a health problem or condition (Statistics Canada, 2009b). Moreover, PALS 2006 was designed to provide essential information on: the prevalence of various disabilities, support for persons with disabilities, their employment profile and their income and participation in society (Statistics Canada, 2009b). Data collected from PALS 2006 is primarily used to inform social policy development at different levels of government as well as to inform the planning, creation, and evaluation of programs and services for individuals with disability while creating a national data source for research in the field of disability (Statistics Canada, 2007).

PALS 2006 implemented a two-stage stratified design (Statistics Canada, 2007). Stage one consisted of the distribution of the Long Form Canadian Census and stage two

was to select those individuals who reported “Yes” to at least one of the two disability filter questions during stage one, based on characteristics defining the strata (Statistics Canada, 2007). These characteristics were: age group, province/territory, severity of disability (according to the Canadian 2006 Census defined by response categories of “Often” and “Sometimes”) and probability of selection in stage one (Statistics Canada, 2007).

In the 2006 Census, there were two ‘trigger questions’ to include individuals in the PALS population. They were:

1. Do you have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities? 1= “Yes, sometimes”, 2= “Yes, often”, 3= “No”.
- 2a. Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do at home? 1= “Yes, sometimes”, 2= “Yes, often”, 3= “No”.
- 2b. Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do at work or at school? 1= “Yes, sometimes”, 2= “Yes, often”, 3= “No”.
- 2c. Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do in other activities, for example, transportation or leisure? 1= “Yes, sometimes”, 2= “Yes, often”, 3= “No” (Statistics Canada, 2007).

PALS 2006 then selected a sample of individuals who answered ‘yes’ to either of the two disability filter questions on the Canadian Census to participate in the survey (Statistics Canada, 2007). This database focuses on the participation of Canadian persons with activity limitations. These questions included on the Canadian Long Form Census do not provide

any information that would allow one to draw a conclusion on the type of disability, which would result in the individual experiencing activity limitations.

4.3 Target Population

The Census was used as a sampling framework for the PALS 2006 target population (Statistics Canada, 2007). The PALS target population included individuals living in private dwellings in the 10 Canadian provinces and 3 Canadian territories, who reported an activity limitation in the census. Those living on First Nations reserves and those who were clientele of institutions were not part of the target population due to accessibility. As well, individuals living on military bases, Canadian Armed Forces vessels, merchant vessels, guard vessels, campgrounds and parks were also excluded. PALS 2006 collected their data between October 30th, 2006 and February 2nd, 2007, which provided a sample size of n=38,839 Canadian adults (15 years of age and older). Participation in PALS was entirely voluntary and there was a 73.9% response rate (Statistics Canada, 2007). PALS 2006 identified its target population by using the Canadian Census as a sampling frame. The PALS 2006 data was collected by conducting telephone interviews in either of the official languages with the interviewer using a computer-assisted questionnaire to complete each survey (Statistics Canada, 2007). The use of the computer-assisted method improved the accuracy of the survey data collected by telephone because it provided an appropriate path that the interviewer followed based on the participants' answers (Statistics Canada, 2007). Due to challenges PALS 2006 faced in collecting data from the territories, such as limited households with telephones and language barriers (many only spoke their aboriginal language) interviews were conducted from regional offices where interviewers were able to communicate with the participants using their aboriginal language (Statistics Canada, 2007).

Moreover, proxy interviews were permitted if a respondent was absent for the duration of the survey, was unable to speak English or French, or was unable to participate due to a mental or physical disability (Statistics Canada, 2007). The proxy respondent was required to be an individual who was a care giver, child, parent or spouse and who was capable to respond on their behalf since this individual was most knowledgeable about the individual's challenges and difficulties faced due to their activity and participation limitations (Statistics Canada, 2007).

Each of the 38,839 respondents was assigned a weight to represent individuals who were not sampled, as well as, themselves. The application of weights to the data was necessary to estimate parameters of interest (e.g., rate of chronic pain) at the population level. The application of weights to the data was also necessary to maintain consistency in the estimations. PALS 2006 provided sampling weights in the master file to be able to provide population estimates. The provided weights were calculated by Statistics Canada in a three stage process: first, the initial weight was used (which is the inverse of the inclusion probability based on the sampling design), next adjustments were made for non-response, and finally post-stratification was applied to ensure that the sum of the final weights for the participants was equal to the population counts acquired from the 2006 Canadian Census (Statistics Canada, 2007).

Due to a clustering and stratification methodology applied by Statistics Canada to select the sample for PALS 2006, accurate variance estimation for population cannot be achieved by applying a simple formula. To generate accurate variance estimates a bootstrap method was applied consisting of selecting 1,000 subsamples with replacement from the main sample.

4.4 Study Sample

The study population consists of Canadians who reported having a disability and who were at least 55 years of age at the time of the PALS in 2006. However, those individuals who only reported having pain related disability were excluded from the sample, as they would skew the results.

4.5 Study Measure

HRQoL, chronic pain, disability measures, and demographic characteristics are the four areas of focus in the study measurements (see appendix D for list of variable). Each of the following categories will be further explained in the following sections. All measures in this research which included the following response types: “Blank”, “Don’t know”, “Not applicable”, “Not asked”, “Not stated”, and “Refusal” were re-coded as “Missing”.

However, due to the requirement for weighting in PALS 2006, if the demographic information of ‘age’ and ‘sex’ consisted of “Non-response”, “Missing” or “Invalid”, the data was imported from the 2006 Canadian Census data (Statistics Canada, 2007). In addition, those individuals who responded to only having chronic pain as a disability were eliminated from the sample, as they would confound the results.

4.6.1 Dependent Variable

4.6.1.1 Health Related Quality of Life

In the proposed study, HRQoL served as the outcome measure. It is measured based on a single question from the Leisure and Recreation Module in PALS 2006. Participants were asked to rate their general health from, “Excellent”, “Very good”, “Good”, “Fair”, “Poor”, to “Never/ Don’t know/ Refusal” (Statistics Canada, 2007). This variable was collapsed into “Positive HRQoL” which included “Excellent”, “Very good”, “Good” self-

rated health and “Negative HRQoL” which included “Fair”, and “Poor” self-rated health. Prior research has assessed HRQoL in a similar fashion (e.g., Roychowdhury, Hayden, & Liepa, 2003; Jammoom, et al., 2008; Azarkeivan, Hajibeigi, Alavian, Lankarani, & Assari, 2009).

4.7. Independent Variables

4.7.1 Sociodemographic Variables

The sociodemographic variables are: age, sex, education, marital status, total household income and social network.

4.7.2 Age

Age represented the participant's age at the time of 2006 PALS. The older adults was classified into three age categories: 55 to 64 years of age (young old), 65 to 74 years of age (mid old) and ≥ 75 years of age (old old), as indicated in the literature (Field & Minkler, 1988; Given & Given, 1989). However, there will be an alteration in the age groups as we lower the age range to start at age 55 due to the low sample size.

4.7.3 Sex

Sex is defined as a dichotomous variable (male and female). Male coded as 0 and female coded as 1.

4.7.4 Education

Participants were asked to identify their highest level of completed education. Due to the small sample size in the PALS 2006 ordinal scale for this variable, it was scaled into a categorical scale. PALS 2006 constructed the responses as: “bachelor's degree”, “certificate or diploma above bachelor”, “certificate or diploma below bachelor”, “college, CEGEP or other non-university certificate or diploma from a program of 3 months to less than 1 year”,

“college, CEGEP or other non-university certificate or diploma from a program of 1 year to 2 years”, “college, CEGEP or other non-university certificate or diploma from a program of more than 2 years”, “degree in medicine, dentistry, veterinary medicine or optometry”, “earned doctorate degree”, “high school graduation certificate or equivalency certificate”, “master’s degree”, “other trades certificate or diploma”, “registered apprenticeship certificate or diploma”, and/or “not stated, none, not applicable”. Once again, due to the sample sizes, this variable was collapsed into three groups: 1) less than secondary school; 2) secondary school graduate/no post-secondary education; and 3) some post-secondary education and/or post-secondary degree/diploma. The grouping of the levels of education follows previous research by Last (1983).

4.7.5 Total Household Income

Individuals’ socioeconomic status was measured based on their total household income. Household income quartiles were used to classify individuals into one of the following four income groups: low (\$0-\$22445), lower middle (\$22446-\$42415), upper middle (\$42416-\$72040) and high (\$72041 and above). This is of importance as Canadian literature suggests that the average hourly wage in 2004 for those individuals with disability fell behind those without disability (Galarneua & Radulescu, 2009).

4.7.2.1 Marital Status

Participants were asked to identify their legal marital status. PALS 2006 constructed responses which included: “divorced”, “legally married (and not separated)”, “never married (single)”, “separated, but still legally married”, “widowed”, and/or “not stated, none, not applicable”. Consistent with previous literature (Brattberg, et al., 1989; Menec, Shooshtari, Nowicki, & Fournier, 2010), we derived a new variable to define marital status as a

dichotomous variable with two response categories: 1) single (included divorced, never married, single, and widowed) and 2) married/living together (included legally married and not separated, and separated, but still legally married).

4.7.2.2 Social Network

Participants were asked to identify the number of close friends they had not including relatives with whom they felt they could speak to at ease about what was on their mind or call for help. PALS 2006 constructed responses which included: “None”, “1 to 2”, “3 to 5”, “6 to 10”, “11 to 20”, and “More than 21”. This research maintained the same grouping of number of social networks provided by PALS 2006.

4.7.3 Pain Related variables

4.7.3.1 Chronic Pain

PALS 2006 includes a pain filter section where all participants were asked if they were currently suffering from a pain or discomfort that was always present or whether they had reoccurring periods of pain or discomfort from time to time. The outcome measure of pain that was used in this research will be the derived variable of pain, which is based on individual responses to the pain related screening questions on the survey. The derived variable of pain in PALS 2006, categorized respondents based on their degree of severity of pain: “No disability”, “Less severe”, “More severe”.

4.7.4 Disability Related Measures

This research defined disability by type and severity of disability as described in PALS 2006. Below is a description of the disability measures.

4.7.4.1 Type of Disability

PALS 2006 incorporated the definition used by the ICF to conceptualize disability as an activity limitation and/or participation restriction associated with a mental or physical condition (Statistics Canada, 2007). In the 2006 adult PALS, disability type was identified in the following manner. First, the two filter questions from the Long Form Canadian Census 2006 were used and followed by a sequence of detailed screening questions. These were included to gather more information in order to begin determining the extent and nature of the disability (Statistics Canada, 2007). If it was concluded that the participant had a disability, several follow up questions, which were related to, the disability and its impact on specific aspects of the participant's daily life were included.

If an individual reported having a disability on the Long Form Canadian Census in 2006 and reported no disability in PALS 2006, this was reported as a false positive. If and when a false positive was detected these participants were slotted into a false positive module. The false positive module was comprised of questions used to aid in the determination of why a positive response was recorded on the 2006 Canadian Census and was negatively reported on PALS 2006 (Statistics Canada, 2007). If the presence of disability was established, the specific type of disability was then determined from the responses provided in the screening questions. PALS 2006 described ten types of disability: agility, developmental, hearing, learning, memory, mobility, pain, psychological, seeing, speech, and unknown (Appendix E). PALS 2006 has implemented a general, broad category approach to describe types of disability. PALS 2006 implemented filter questions for each of the nine types of disability categories and within each of the nine categories the filter questions asked individuals if they experienced any activity limitation that related to the type

of disability. At this point it was determined by PALS 2006 that if any individual answered yes to those questions they did in fact have a disability, which correlated to that specific type of disability. Therefore, PALS 2006 does not necessarily determine disability based on the type of chronic conditions, rather it examines the limitations that individuals have regardless of what type of disability they have been labeled with.

Within this research, disability was also comprised of nine types of disability: agility, communication (speech), developmental, emotional (psychological), hearing, learning, memory, mobility, pain, seeing, as well as, unknown. Pain was not included since this research was testing pain's relationship to those types of disabilities.

4.7.4.2 Severity of Disability

PALS 2006 contained a severity of disability variable, which was a derived variable. Severity of disability is determined based on a derived variable from the participants' responses to filter questions in Section A and screening questions in Section B, on an individual basis, in PALS 2006. There were four categories detailing the severity of the disability: "Mild", "Moderate", "Severe", and "Very severe". Degree of disability was coded into a binary variable: "mild to moderate" and "severe to very severe". The severity level that an individual experienced was attributed to the cumulative effect of multiple disabilities or the overall effect of one significant disability and was independent of specific type(s) of disability (Statistics Canada, 2007). The examination of the cumulative effect of multiple disabilities is important as co-morbid mental and physical disabilities have the potential to cause greater disability than the occurrence of each type of disability on its own (Bair, Robinson, Katon, & Kroenke, 2003).

4.7.4.3 Onset of Disability

Age of onset of disability is a significant factor that contributes to each individual's experience of living with a disability. The age of onset affects the individual's experiences over time and can impact an individual's opportunities. Participants were asked at what age they first started having any difficulties or activity limitations. PALS 2006 constructed responses that allowed individuals to respond with any age. Research by Jammoom et al. (2008) classified early onset of disability as those individuals who reported having an activity limitation beginning between birth to age 21 while late or adult onset was an activity limitation beginning at 22 years and older. For the purpose of this study, age at disability onset was defined in the following five categories: birth through 18 years of age, ages 19 to 54, ages 55 to 64, ages 65 to 74 and 75 years of age and older. This age stratification design follows a similar complex used in past studies such as the one by Jammoom, et al. (2008).

4.8 Ethical Approval

Approval was granted through Statistics Canada's Research Data Centre (RDC) at the University of Manitoba to access PALS 2006 data. The Statistics Act was followed during the conduction of this research. Statistics Canada prohibits researchers using Statistics Canada's data from releasing any data, which could be used to determine the identity of a business, individual, and organization without their prior knowledge or written consent (Statistics Canada 2007). Output is not released if it can lead to direct or residual disclosure of identifiable information. Frequency tables must represent a cell count of 10 or greater un-weighted, and only weighted and rounded (to base 10) output is allowed for release with the PALS. Ethics approval for this study was obtained from the University of Manitoba, Joint Faculty Research Ethic Board (Appendix F).

4.10 Analysis

Weighted data was used to provide an estimate on the number and proportion of older Canadian adults with disability with and without chronic pain related disability. In addition, cross-tabulations and chi-square tests were conducted to examine and compare characteristics of older Canadian adults with disability with no chronic pain, less severe chronic pain and severe chronic pain by selected variables (age, sex, education, total household income, marital status, social network, type of disability, severity of disability, onset of disability, and HRQoL). As well, cross-tabulations and chi-square tests were conducted to examine the characteristics of older Canadian adults with disability 55 years of age and older, as well as their report of either positive or negative HRQoL. Logistic Regression analysis was used to examine the independent effects of chronic pain on HRQoL controlling for the effects of a number of variables including (demographic and social characteristics and disability related measures). Controlling for these variables allowed for balancing the effects across the population and then to ignore those variables and examine the relationship between the independent variable (chronic pain) and the dependent variable (HRQoL). To conduct the multiple regression analysis, hierarchical multiple logistic regression models were implemented. The hierarchical regression allows the researcher to evaluate the relationship between an independent variable (chronic pain) and the dependent variable (HRQoL), controlling for the impact of a different set of independent variables (demographic and social characteristics and disability related measures) and their impact on the dependent variable. This model was created in a two-block sequence: the control variables were entered in block 1 and the predictor variable was entered in block 2. Block (1) included demographic and social characteristics (age, sex, education, total household

income, marital status, and social network) and disability related measures (type of disability, severity of disability, and onset of disability). Block (2) included demographic and social characteristics (age, sex, education, total household income, marital status, and social network), disability related measures (type of disability, severity of disability, and onset of disability) and degree of chronic pain. The odds ratio provided in the logistic regressions measures the odds of association; therefore, the odds of something taking place in relation to the ratio of the number of times an event did and did not occur. To fully account for the effects of survey sampling design, bootstrapped weights were applied during the analysis to ensure accurate estimation of variance, and 95% confidence intervals.

Section 5 Results

5.1 Description of the Study Population: Older Canadian Adults with Disability

The characteristics of the study population for the analysis of older Canadian adults with disability are displayed in Tables 3 and 4. The demographic and social characteristics of the study population are summarized in Table 3. According to the data presented in Table 4, the most common type of disability reported was mobility disability at 75.39% [(95% CI: 73.94-76.79); n=1,947,000] of the study population, followed by agility disability at 72.50% [(95% CI: 70.97-73.94); n=1,871,740]. As shown in Table 4 an estimated 59.60% [(95% CI: 58.05-61.13); n=1,539,220] of the population reported mild to moderate disability and an estimated 40.40% [(95% CI: 38.87-41.95); n=1,043,290] reported severe to very severe disability. Onset of disability presented in Table 4 displays that one third of the study population (33.10%) reported that their disability was developed between the ages of 19 and 54. An estimated 31.37% (29.73-33.07; n=804,540) of the study population reported no

pain; 45.34% [(95% CI: 43.06-47.10); n=1,162,790] reported less severe pain, and 23.29% [(95% CI: 21.88-24.75); n=597,170] reported more severe pain.

Table 3. Distribution of Study Population by Demographic and Social Characteristics

Variables	Estimated Population	Weighted (%)	Confidence Intervals
Total	2582500	100%	95%
Age			
55 to 64	824,920	31.94	(31.30 - 32.59)
65 to 74	739,500	28.64	(28.09 - 29.18)
75 +	1,018,090	39.42	(38.79 - 40.06)
Sex			
Female	1,454,860	56.22	(55.58 - 56.22)
Male	1,130,640	43.78	(43.14 - 44.42)
Education			
Less than high school	533,290	34.77	(32.68 - 36.92)
High school	245,830	16.03	(14.35 - 17.86)
More than high school	754,680	49.20	(46.90 - 51.51)
Total Household Income			
\$0 to \$22,445	550,550	21.34	(19.97 - 22.77)
\$22,446 to \$42,415	738,150	28.61	(27.18 - 30.08)
\$42,416 to \$72,040	673,440	26.10	(24.64 - 27.62)
\$72,041+	618,010	23.95	(22.48 - 25.49)
Marital Status			
Single	1,167,880	45.23	(43.63 - 46.84)
Married/Living together	1,414,160	54.77	(53.16 - 56.37)
Social Network			
None	191,020	9.95	(8.86 – 11.15)
1 to 2 Friends	418,030	21.76	(20.13 – 20.13)
3 to 5 Friends	617,650	32.16	(30.49 – 33.88)
6 to 10 Friends	388,060	20.20	(18.80 – 21.68)
11 to 20 Friends	165,260	8.60	(7.73 – 9.56)
21+ Friends	140,700	7.33	(6.46 – 8.30)
<i>Note.</i> Missing values for total household income were not included as there was less than 5% missing.			

Table 4. Distribution of study population by Type, Severity and Onset of Disability

Variables	Estimated Population	Weighted (%)	Confidence Intervals
Total	2,582,500	100%	95%

Agility Disability			
Yes	1,871,740	72.48	(70.97 – 73.94)
No	710,770	27.52	(26.06 – 29.03)
Communication Disability			
Yes	224,100	8.68	(7.71 - 9.75)
No	2,363,190	91.32	(90.25 – 92.29)
Developmental Disability			
Yes	26,470	1.04	(0.70 – 1.53)
No	2,527,660	98.96	(98.47 – 99.30)
Emotional Disability			
Yes	204,770	8.00	(7.06 – 9.04)
No	2,356,010	92.00	(90.96 – 92.94)
Hearing Disability			
Yes	966,420	37.52	(35.89 – 39.17)
No	1,609,540	62.48	(60.83 – 64.11)
Learning Disability			
Yes	212,210	8.24	(7.28 – 9.31)
No	2,363,190	91.76	(90.69 – 92.72)
Memory Disability			
Yes	261,760	10.24	(9.19 – 11.40)
No	2,293,550	89.76	(88.60 – 90.81)
Mobility Disability			
Yes	1,947,000	75.39	(73.94 – 76.79)
No	635,500	24.61	(23.21 – 26.06)
Seeing Disability			
Yes	515,270	20.02	(18.66 – 21.45)
No	2,058,500	79.98	(78.55 – 81.34)
Unknown Disability			
Yes	68,170	2.64	(2.17 - 3.21)
No	2,514,340	97.36	(96.79 - 97.83)
Severity of Disability			
Mild to moderate	1,539,220	59.60	(58.05 - 61.13)
Severe to very severe	1,043,290	40.40	(38.87 - 41.95)
Onset of Disability			
Birth to 18 years	148,880	6.12	(5.30 – 7.06)
19 to 54 years	804,680	33.10	(31.65 – 34.59)
55 to 64 years	551,640	22.69	(21.25 – 24.21)
65 to 74 years	497,590	20.47	(19.17 – 21.83)
75+ years	428,040	17.61	(16.41 – 18.88)

5.1.2 Description of the Study Population: Demographic and Social Support Characteristics, Disability Related Measures and Chronic Pain

Demographic and social support characteristics and disability related measures are presented in the following cross-tabulation tables (Tables 5 and 6) for those individuals who experienced severe chronic pain, less severe chronic pain, and no chronic pain. The chi-square results display the association between demographic and social support characteristics and disability related measures, HRQoL, and chronic pain as the outcome.

As presented in Table 5, individuals were less likely to report severe chronic pain with increasing age. The observed association was statistically significant ($X^2=13.51$; $p=0.0000$). There was a statistically significant association between severity of chronic pain and age. There was a significant association ($X^2=21.08$; $p=0.0000$) between severity of chronic pain and sex; females were more likely than males to report more severe chronic pain (24.7% vs. 21.5%). There was also a statistically significant association between severity of chronic pain and education ($X^2=4.00$; $p=0.0032$) as well as severity of chronic pain and social network ($X^2=4.25$; $p=0.0000$). As presented in Table 6, of all types of disabilities studied, there were only two types that were not statistically associated with reported chronic pain: developmental disability ($X^2=1.72$; $p=0.1792$) and hearing disability ($X^2=2.30$; $p=0.1008$). There was a statistically significant association between HRQoL and chronic pain ($X^2=207.27$, $p=0.0000$). Of those who reported severe chronic pain ($n=144,680$), only an estimated 10.8% reported positive HRQoL. Of those who reported less severe chronic pain, a higher proportion, 47.1% reported positive HRQoL. Of those who reported no chronic pain, an estimated 42.1% reported positive HRQoL.

Table 5. Chronic Pain by Demographic and Social Characteristics, Canadians with Disability Aged 55+, 2006

Variables	Severe Chronic Pain		Less Severe Chronic Pain		No Chronic Pain		Total	X ²	P Value
	Count	%	Count	%	Count	%			
Age									
55 to 64	229,140	28.0	395,040	48.2	194,850	23.8	819040	13.51	0.000 ***
65 to 74	155,590	21.2	355,370	48.4	223,730	30.5	734700		
75 +	212,440	21.0	412,370	40.8	385,950	38.2	1010760		
Sex									
Female	356,720	24.7	702,620	48.7	384,580	26.6	1,443,910	21.08	0.000 ***
Male	240,450	21.5	460,170	41.1	419,960	37.5	1,120,580		
Education									
Less than high school	122,490	23.3	248,590	47.2	155,570	29.5	526,640	4.00	0.003 **
High school	37,080	15.1	127,990	52.2	80,130	32.7	245,200		
More than high school	188,760	25.2	338,000	45.1	222,850	29.7	749,620		
Total Household Income									
\$0 to \$22,445	137,590	25.1	244,820	44.7	165,260	30.2	547,670	0.61	0.724
\$22,446 to \$42,415	170,850	23.3	321,040	43.8	241,100	32.9	732,990		
\$42,416 to \$72,040	153,740	23.1	303,380	45.6	208,830	31.4	665,940		
\$72,041+	134,510	21.9	292,200	47.5	188,830	30.7	615,540		
Marital Status									
Single	272,360	23.5	520,420	44.9	366,060	31.6	1,159,130	0.9143	0.914
Married/Living together	324,820	23.1	641,740	45.7	438,350	31.2	1,404,910		
Social Network									
None	51,330	27.0	70,910	37.4	67,610	35.6	189,850	4.25	0.000 ***
1 to 2 Friends	114,320	27.5	185,470	44.6	116,450	28.0	416,240		
3 to 5 Friends	133,550	21.7	296,840	48.3	184,180	30.0	614,570		
6 to 10 Friends	68,070	17.6	194,060	50.2	124,510	32.2	386,640		
11 to 20 Friends	29,910	18.1	71,980	43.6	63,190	38.3	165,080		
21+ Friends	22,930	16.4	63,520	45.4	53,420	38.2	139,870		

Note. Totals may not sum to 100% due to rounding.

***p<0.001, **p<0.01, *p<0.05

Table 6. Chronic Pain by Type, Severity and Onset of Disability, Canadians with Disability Aged 55+, 2006

Variables	Severe Chronic Pain		Less Severe Chronic Pain		No Chronic Pain		Total	X ²	P Value
	Count	%	Count	%	Count	%			
Agility Disability									
Yes	568,540	30.6	882,440	47.5	408,290	22.0	1,859,260	290.98	0.000
No	28,630	4.1	280,350	39.8	396,250	56.2	705,230		***
Communication Disability									
Yes	77,300	35.0	84,760	38.4	58,690	26.6	220,750	8.94	0.000
No	519,870	22.2	1,077,650	46.0	745,590	31.8	2,343,120		***
Developmental Disability									
Yes	5,890	22.6	7,370	28.2	12,840	49.2	26,100	1.72	0.179
No	582,160	23.2	1,142,870	46.2	785,070	31.3	2,510,100		
Emotional Disability									
Yes	102,820	50.3	72,790	35.6	28,630	14.0	204,240	28.84	0.000
No	486,880	20.8	1,081,200	46.2	771,980	33.0	2,340,060		***
Hearing Disability									
Yes	221,040	23.0	416,250	43.4	322,560	33.6	959,840	2.30	0.100
No	375,880	23.5	743,450	46.5	478,840	30.0	1,598,160		
Learning Disability									
Yes	85,020	40.3	70,270	33.3	55,480	26.3	210,760	15.54	0.000
No	507,050	21.6	1,091,840	46.5	748,290	31.9	2,347,180		***
Memory Disability									
Yes	95,670	37.0	99,890	38.7	62,760	24.3	258,320	16.23	0.000
No	490,400	21.5	1,052,360	46.1	737,660	32.3	2,280,420		***
Mobility Disability									
Yes	575,200	29.8	913,960	47.3	442,950	22.9	1,932,110	291.27	0.000
No	21,970	3.5	248,820	39.3	361,590	57.2	63,2380		***
Seeing Disability									
Yes	166,420	32.4	205,970	40.1	141,450	27.5	513,840	14.61	0.000
No	430,320	21.1	950,080	46.5	663,090	32.4	2,043,500		***

Unknown Disability	0	0.0	0	0.0	66,760	100	66,760	51.14	0.000
Yes	5,971,71	23.9	1,162,79	46.6	737,780	28.5	2,497,740		***
No	0		0						
Severity of Disability									
Mild to moderate	49,980	3.3	782,400	51.3	694,120	45.5	1,526,500	607.62	0.000
Severe to very severe	547,190	52.7	380,390	36.6	110,420	10.6	1,038,000		***
Onset of Disability									
Birth to 18 years	36,060	24.3	47,880	32.3	64,490	43.4	148,430	12.96	0.000
19 to 54 years	240,550	30.1	391,610	49.0	167,270	20.9	799,430		***
55 to 64 years	116,140	21.1	279,170	50.8	154,160	28.1	549,470		
65 to 74 years	96,510	19.5	224,510	45.4	173,980	35.1	459,000		
75+ years	92,940	20.0	164,390	38.9	165,800	39.2	423,120		
<i>Note.</i> Totals may not sum to 100% due to rounding.									
***p<0.001, **p<0.01, *p<0.05									

5.1.3 Description of the Study Population: Health Related Quality of Life

The majority of the study population [(56.42%); 95% CI: 54.83-58.00; n=1,346,520] reported positive HRQoL and 43.58% [(95% CI: 42.00-45.17); n=1,040,020] reported negative HRQoL. Tables 7 and 8 summarize the information on the demographic and social support characteristics and disability related measures in relation to the HRQoL for the study population. The chi-square results display the association between demographic and social support characteristics, disability related measures, and HRQoL as the outcome.

There was not a statistically significant association between individuals' age, sex and their HRQoL; however, an individual's level of education ($X^2=4.32$; $p=0.0135$), their household income ($X^2=12.00$; $p=0.0000$), marital status ($X^2=7.18$; $p=0.0075$), and frequency of social network ($X^2=10.29$; $p=0.0000$) were significantly associated with HRQoL (Table 7). As displayed in Table 8, all types of disability displayed a statistically significant association with HRQoL except for developmental disability ($X^2=1.81$; $p=0.1790$) and hearing disability ($X^2=0.41$; $p=0.5237$). There was a statistically significant association

between the severity of disability and HRQoL, with a much larger proportion of those with severe to very severe disability (65.9%) reporting negative HRQoL compared with those who reported mild to moderate severity of disability (28.9%).

Table 7. Health Related Quality of Life by Demographic and Social Characteristics, Canadians with Disability Aged 55+, 2006

Variables	HRQoL Negative		HRQoL Positive		Total	X ²	P Value
	Count	%	Count	%			
Age							
55 to 64	345,650	45.4	415,800	54.6	761,440	1.37	0.2536
65 to 74	287,620	42.1	369,320	57.9	683,940		
75 +	406,750	43.2	534,400	56.8	941,150		
Sex							
Female	593,380	44.1	752,120	55.9	1,345,500	0.48	0.4872
Male	446,640	42.9	594,400	57.1	1,041,040		
Education							
Less than high school	210,390	41.5	296,130	58.5	506,520	4.32	0.0135 *
High school	76,430	33.2	154,000	66.8	230,430		
More than high school	290,280	41.8	403,970	58.2	694,250		
Total Household Income							
\$0 to \$22,445	250,730	50.5	245,880	49.5	496,610	12.00	0.0000 ***
\$22,446 to \$42,415	319,800	47.0	360,070	53.0	679,870		
\$42,416 to \$72,040	265,730	41.7	370,780	58.3	636,500		
\$72,041+	368,930	35.4	368,930	64.6	571,250		
Marital Status							
Single	490,930	46.1	572,920	53.9	10,635,850	7.18	0.0075 **
Married/Living together	548,680	41.5	773,600	58.5	1,322,280		
Social Network							
None	96,470	51.4	91,330	48.6	187,800	10.29	0.0000 ***
1 to 2 Friends	205,810	49.9	206,810	50.1	412,630		
3 to 5 Friends	240,530	39.2	373,170	60.8	613,700		
6 to 10 Friends	144,700	37.4	242,080	62.2	386,770		
11 to 20 Friends	49,180	30.0	114,990	70.0	164,170		
21+ Friends	52,250	58.6	88,210	41.4	140,460		
<i>Note.</i> Totals may not sum to 100% due to rounding. ***p<0.001, **p<0.01, *p<0.05							

Table 8. Health Related Quality of Life by Type, Severity and Onset of Disability, Canadians with Disability Aged 55+, 2006

Variables	HRQoL Negative		HRQoL Positive		Total	X ²	P Value
	Count	%	Count	%			
Agility Disability							
Yes	896,360	52.1	823,660	47.9	1,720,030	298.90	0.0000**
No	143,650	21.6	522,860	78.4	666,510		*
Communication Disability							
Yes	125,560	61.3	79,160	38.7	204,720	34.96	0.0000**
No	914,250	41.9	1,267,100	58.1	2,181,360		*
Developmental Disability							
Yes	13,620	56.3	9,730	41.7	23,360	1.81	0.1790
No	1,015,210	43.2	1,332,570	56.8	2,347,790		
Emotional Disability							
Yes	128,760	68.0	60,570	32.0	189,330	64.54	0.0000**
No	903,900	41.3	1,284,450	58.7	2,188,350		*
Hearing Disability							
Yes	38,520	42.8	510,700	57.2	382,520	0.41	0.5237
No	653,890	44.0	833,070	56.0	653,890		
Learning Disability							
Yes	121,120	63.1	70,760	36.9	191,880	40.53	0.0000**
No	913,180	41.7	1,275,180	58.3	2,188,360		*
Memory Disability							
Yes	150,990	65.8	78,470	34.2	229,460	70.50	0.0000**
No	877,400	40.9	1,265,400	59.1	2,142,800		*
Mobility Disability							
Yes	936,350	52.4	851,390	47.6	1,787,750	366.58	0.0000**
No	103,660	17.3	495,130	82.7	598,790		*
Seeing Disability							
Yes	262,790	56.0	206,590	44.0	469,380	46.02	0.0000**
No	776,060	40.5	1,139,700	59.5	1,915,750		*

Unknown Disability	8,870	14.4	52,960	85.6	61,840	43.93	0.0000**
Yes	1,031,140	44.4	129,350	55.6	2,324,700		*
No							
Severity of Disability							
Mild to moderate	415,820	28.9	1,023,000	71.1	1,346,520	467.71	0.0000**
Severe to very severe	624,200	65.9	323,510	34.1	1,040,020		*
Onset of Disability							
Birth to 18 years	55,040	39.3	85,180	60.7	140,220	1.32	0.2601
19 to 54 years	347,890	46.2	404,850	32.0	752,740		
55 to 64 years	228,150	44.4	285,840	22.6	513,990		
65 to 74 years	210,070	44.7	260,050	55.3	470,120		
75+ years	162,160	41.3	230,620	58.7	392,780		
<i>Note.</i> Totals may not sum to 100% due to rounding.							
***p<0.001, **p<0.01, *p<0.05							

5.4 Results from the Multiple Logistic Regression Modeling

The main objective of this research was to examine the relationship between chronic pain and HRQoL among Canadians with disability 55 years of age and older. Hierarchical multiple logistic regression analyses were conducted using SUDAAN, which provides the Cox & Snell R^2 value as the measurement of how much of the observed variability in the outcome variable is explained by the independent variables in the model (Research Triangle Institute, 2001). This model was created in a two-block sequence: the control variables were entered in Block 1 and the predictor variable was entered in Block 2. Block (1) included demographic and social characteristics (age, sex, education, total household income, marital status, and social network) and disability related measures (type of disability, severity of disability, and onset of disability), presented in Table 9. Block (2) included demographic and social characteristics (age, sex, education, total household income, marital status, and social network) and disability related measures (type of disability, severity of disability, and onset of disability) as well as degree of chronic pain, presented in Table 10. The Cox and

Snell R^2 for each of the two models were: 19.6% for Block 1 and 21.3% for Block 2. The odds ratios and their 95% confidence ratios were used to identify significant independent variables.

Results from the multiple logistic regression examining Block 1 factors as predictors of HRQoL are presented in Table 9. According to the data presented in this table, it was found that individuals whose total household income was between \$22,446 to 42,415 had greater odds [AOR=1.62; (95% CI: 1.19-2.20)] of reporting negative HRQoL compared to those whose total household income was \$72,041 and more. It was also found that those individuals with agility [AOR=1.98; (95% CI: 1.49-2.64)] and mobility [AOR=2.81; (95% CI: 2.05-2.84)] disabilities had the greatest odds of reporting negative HRQoL. Individuals who reported severe to very severe disability had significantly greater odds [AOR=2.62; (95% CI: 2.04-3.36)] of reporting negative HRQoL relative to those with mild to moderate severity of disability.

Table 10 summarizes the results of the most comprehensive logistic regression model (Block 2), which examines the predictors of reporting negative HRQoL among older Canadian adults with disability 55 years of age and older. After controlling for all of the factors in Block 1 (Table 9), the independent effect of chronic pain (the main predictor of interest) was examined. With decrease in total household income the likelihood of reporting negative HRQoL increases. When compared to those individuals whose household income was \$72,041 or greater, those whose total household income was \$0 to \$22,445 had significantly greater odds of reporting negative HRQoL. Those who reported having an agility disability had greater odds [AOR=1.85; (95% CI= 1.39-2.47)] of reporting negative HRQoL. Compared to individuals without a mobility disability, the greatest odds of

reporting negative HRQoL were observed among those who reported a mobility disability [AOR=2.62; (95% CI=1.91-3.61)]. Relative to those who reported no and less severe disability, those who reported severe disability had the greatest odds of negative HRQoL [AOR=1.51; (95% CI=1.11-2.06)]. Table 10 displays that with the addition of chronic pain, being a female decreases the chance of reporting negative HRQoL compared to males (95% CI= 0.55-0.88).

The association between learning disability and negative HRQoL was not statistically significant [AOR=1.51; ($p > 0.95$)] in Block 1, which examined all the studied variables except chronic pain (Table 9). In Block 2 (Table 10), which included chronic pain, the association between learning disability and negative HRQoL displayed borderline significance [AOR=1.56; (95% CI= 0.95-2.56); $p = 0.0759$]. These results suggest that learning disabilities are not a predictor of negative HRQoL; however, relative to chronic pain, HRQoL tends to decrease when learning disabilities are present in the older Canadian adult population.

It was found there is a highly significant independent effect of chronic pain on negative HRQoL. The results displayed that those with more severe chronic pain had greater odds of reporting negative HRQoL, which was 3.34 (95% CI= 2.28-5.15) times higher than the odds of reporting negative HRQoL by those with no chronic pain. Those who reported less severe chronic pain also had greater odds of reporting negative HRQoL, which was significantly higher than that of the reference group of no chronic pain [AOR=1.39; (95% CI= 1.02-1.88)]. Block 2 displays that chronic pain was significantly associated with negative HRQoL, and a dose-response relationship was observed: the adjusted odds ratio for

negative HRQoL was 1.39 for less severe chronic pain, and 3.34 for more severe chronic pain when compared to the reference group.

Table 9. Predictors of Negative HRQoL for Older Canadian Adults with Disability Aged 55+, 2006 (Block 1)

Predictor Variables	AOR	(95% CI)	P Value
Age			
55 to 64	1.00	(1.00-1.00)	-
65 to 74	0.86	(0.65-1.13)	0.2839
75 +	0.87	(0.57-1.31)	0.4970
Sex			
Female	0.71	(0.56-0.89)	0.0037
Male	1.00	(1.00-1.00)	-
Education			
Less than high school	0.89	(0.70-1.14)	0.3566
High school	0.78	(0.56-1.09)	0.1418
More than high school	1.00	(1.00-1.00)	-
Total Household Income			
\$0 to \$22,445	1.55	(1.04-2.32)	0.0316
\$22,446 to \$42,415	1.62	(1.19-2.20)	0.0020
\$42,416 to \$72,040	1.29	(0.98-1.71)	0.0739
\$72,041+	1.00	(1.00-1.00)	-
Marital Status			
Single	1.00	(1.00-1.00)	-
Married/Living together	1.13	(0.89-1.45)	0.3238
Social Network			
None	0.99	(0.56-1.72)	0.9609
1 to 2 Friends	1.07	(0.66-1.73)	0.7935
3 to 5 Friends	0.92	(0.58-1.46)	0.7275
6 to 10 Friends	0.96	(0.59-1.56)	0.8745
11 to 20 Friends	0.57	(0.34-0.97)	0.0400
21+ Friends	1.00	(1.00-1.00)	-
Agility Disability			
Yes	1.98	(1.49-2.64)	0.0000
No	1.00	(1.00-1.00)	-
Communication Disability			
Yes	1.05	(0.64-1.73)	0.8470
No	1.00	(1.00-1.00)	-

Developmental Disability			
Yes	1.02	(0.14-7.20)	0.9841
No	1.00	(1.00-1.00)	-
Emotional Disability			
Yes	1.30	(0.84-2.03)	0.2428
No	1.00	(1.00-1.00)	-
Hearing Disability			
Yes			
No	0.96	(0.76-1.22)	0.7580
	1.00	(1.00-1.00)	-
Learning Disability			
Yes			
No	1.51	(0.91-2.51)	0.1077
	1.00	(1.00-1.00)	-
Memory Disability			
Yes			
No	1.30	(0.82-2.08)	0.2685
	1.00	(1.00-1.00)	-
Mobility Disability			
Yes			
No	2.81	(2.05-2.84)	0.0000
	1.00	(1.00-1.00)	-
Seeing Disability			
Yes	1.30	(0.99-1.69)	0.0568
No	1.00	(1.00-1.00)	-
Unknown Disability			
Yes	0.83	(0.34-1.99)	0.6684
No	1.00	(1.00-1.00)	-
Severity of Disability			
Mild to moderate	1.00	(1.00-1.00)	-
Severe to very severe	2.62	(2.04-3.36)	0.0000
Onset of Disability			
Birth to 18 years	1.00	(1.00-1.00)	-
19 to 54 years	1.02	(0.62-1.69)	0.9375
55 to 64 years	1.19	(0.73-1.95)	0.4880
65 to 74 years	1.17	(0.68-2.02)	0.5695
75+ years	0.91	(0.47-1.76)	0.7715
Intercept	0.09	(0.04-0.20)	0.0000
Cox & Snell R ²	0.196430		

Table 10. Predictors of Negative HRQoL for Older Canadian Adults with Disability Aged 55+, 2006 (Block 2)

Predictor Variables	AOR	(95% CI)	P Value
Age			
55 to 64	1.00	(1.00-1.00)	-
65 to 74	0.89	(0.67-1.17)	0.2839
75 +	0.96	(0.64-1.46)	0.4970
Sex			
Female	0.69	(0.55-0.88)	0.0024
Male	1.00	(1.00-1.00)	-
Education			
Less than high school	0.90	(0.71-1.15)	0.3933
High school	0.85	(0.61-1.18)	0.3258
More than high school	1.00	(1.00-1.00)	-
Total Household Income			
\$0 to \$22,445	1.68	(1.13-2.25)	0.0108
\$22,446 to \$42,415	1.64	(1.20-2.25)	0.0019
\$42,416 to \$72,040	1.30	(0.97-1.73)	0.0748
\$72,041+	1.00	(1.00-1.00)	-
Marital Status			
Single	1.00	(1.00-1.00)	-
Married/Living together	1.12	(0.87-1.43)	0.3851
Social Network			
None	0.97	(0.56-1.67)	0.9087
1 to 2 Friends	1.04	(0.65-1.65)	0.8840
3 to 5 Friends	0.88	(0.56-1.37)	0.5695
6 to 10 Friends	0.94	(0.59-1.50)	0.7992
11 to 20 Friends	0.56	(0.33-0.96)	0.0340
21+ Friends	1.00	(1.00-1.00)	-
Agility Disability			
Yes	1.85	(1.39-2.47)	0.0000
No	1.00	(1.00-1.00)	-
Communication Disability			
Yes	1.19	(0.73-1.93)	0.4861
No	1.00	(1.00-1.00)	-
Developmental Disability			

Yes	1.04	(0.17-6.43)	0.9667
No	1.00	(1.00-1.00)	-
Emotional Disability			
Yes	1.33	(0.85-2.09)	0.2082
No	1.00	(1.00-1.00)	-
Hearing Disability			
Yes			
No	1.03	(0.81-1.32)	0.8042
	1.00	(1.00-1.00)	-
Learning Disability			
Yes	1.56	(0.95-2.56)	0.0759
No	1.00	(1.00-1.00)	-
Memory Disability			
Yes			
No	1.35	(0.83-2.18)	0.2232
	1.00	(1.00-1.00)	-
Mobility Disability			
Yes	2.62	(1.91-3.61)	0.0000
No	1.00	(1.00-1.00)	-
Seeing Disability			
Yes	1.37	(1.05-1.80)	0.0209
No	1.00	(1.00-1.00)	-
Unknown Disability			
Yes	1.00	(0.41-2.42)	1.0000
No	1.00	(1.00-1.00)	-
Severity of Disability			
Mild to moderate	1.00	(1.00-1.00)	-
Severe to very severe	1.51	(1.11-2.06)	0.0097
Onset of Disability			
Birth to 18 years	1.00	(1.00-1.00)	-
19 to 54 years	1.02	(0.61-1.71)	0.9351
55 to 64 years	1.28	(0.77-2.11)	0.3416
65 to 74 years	1.25	(0.72-2.17)	0.4358
75+ years	1.00	(0.51-1.96)	0.9966
Chronic Pain			
More Severe	3.43	(2.28-5.15)	0.000
Less Severe	1.39	(1.02-1.88)	0.0375
No	1.00	(1.00-1.00)	-
Intercept	0.07	(0.03-0.16)	0.0000

Cox & Snell R ²	0.213403		
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Section 6 Discussion

6.1 General Discussion

This is the first Canadian study examining the prevalence of chronic pain among older Canadian adults with disability. This is also the first study examining the relationship between chronic pain and HRQoL among older Canadian adults with disability, using population-based national level data. PALS 2006 provides a national sample that includes individuals with different types of disability residing in private and some collective households across the ten provinces and three territories in Canada (Statistics Canada, 2007b). It was the only national survey that contained detailed information on the type of disability (Statistics Canada, 2007b). The main objective of this study was to examine the relationship between chronic pain and HRQoL among older Canadian adults with disability. Despite the vast literature on chronic pain and HRQoL, little literature exists on the effects of chronic pain on HRQoL among older Canadian adults with disability. The use of data from PALS 2006's made it possible to provide population based estimates of older Canadian adults with disability, and those who reported chronic pain. PALS 2006 had a high response rate for the adult survey (73.9%) (Statistics Canada, 2007) and potential non-response bias of the results were minimized through adjustments in weighting.

The review of the published literature revealed there were a limited number of studies that examined HRQoL among individuals with disability. The literature that was available focused on specific types of disabilities rather than broad categories of disabilities. PALS implemented a general, broad category approach to defining disability. PALS 2006

created a type of disability index, which included 10 of types of disabilities: agility, communication (speech), developmental, emotional (psychological), hearing, learning, memory, mobility, pain, seeing, as well as unknown (see Appendix D for the complete list of types of disabilities and definitions) (Statistics Canada, 2007). Therefore, PALS 2006 classified participants by type of disability in a generalized manner such as agility disability and not specific disabilities such as arthritis.

PALS 2006 implemented a social model of disability approach whereby individuals were not asked to identify their specific type of disability condition. For example, if an individual has arthritis, PALS 2006 did not focus on the condition that was present, as it is known that a condition such as arthritis could be present but not cause disability. PALS 2006 focused on the activity limitations that may be present regardless of the type of condition the individual has to create the type of disability variable. Instead, there were questions used in each of the ten disability categories to determine if activity limitations were present and the type of disability in the general categories was identified using those limitations. This method of categorizing disability was maintained in this study as it follows a more social model of disability perspective, by not labeling an individual with a specific type of disability or impairment, and only evaluating the limitation that is present. This type of categorization is novel. Maintaining this categorization of disability type is significant because it is important that others view individuals with disabilities as heterogeneous. We must focus on the nature of their disability rather than the label of a specific type of disability because inappropriate labeling has the ability to influence the presence of chronic pain. Although in some studies, disabilities are divided into two categories: physical and mental (eg. Ormel, et al., 2008), maintaining the larger subcategories, which were included

in PALS 2006, provides more detailed information than grouping individuals with disability into these two categories. Individuals with mental and/or physical disabilities may have the same or different experiences of participation restrictions and activity limitations (Bickenbach, Chatterji, Badley, & Ustun, 1999), which may affect their overall health and HRQoL.

As aforementioned, the standard definition used to describe chronic pain relies solely on the duration of the pain (Merskey & Bogduk, 1994). Rudy and colleagues (1988) defined chronic pain as “duration of pain 6 months or longer, chronic pain other than headache or related to cancer, and no evidence of active psychosis or acute suicidal risk” for their inclusion criteria. Mantyselka and colleagues (2003) defined chronic pain as a “pain lasting for at least 3 months”. Using this duration-based approach to define chronic pain is opposite to the perspective that chronic pain is multidimensional (Turk & Rudy, 1988). Alternative to the duration-based approach is defining chronic pain with a combination of pain related information such as severity, duration, and prognostic variables (Von Korff, 2011). Prognostic variables refers to defining chronic pain in terms of outcome probabilities and is a new approach to the classification of chronic pain based on the Prognostic Risk Score, which was first introduced by Von Korff and Miglioretti (2005). The Prognostic Risk Score is able to predict clinically significant pain (von Kroff, 2011).

PALS 2006 defined pain as: “Limited in the amount or kind of activities that one can do because of a long-term pain that is constant or reoccurs from time to time (for instance, recurrent back pain).” The pain questions in PALS 2006 examined individuals’ experiences of pain for the six months or more prior to when the survey questions were posed. Therefore, the method in which pain questions were asked better reflected chronic pain

rather than pain, as the standard definition of chronic pain is a pain which lasts for 6 months or longer (Bonica, 1987). PALS 2006 measured severity of pain by assigning points to each of the questions on the basis of severity (Statistics Canada, 2007). As was previously explained in the methodology section, some of the questions were used to measure the frequency of the presence of pain while others measured its intensity; both types of questions were used to calculate the severity scores (Statistics Canada, 2007). Therefore, when no pain was present, no points were assigned to those questions (Statistics Canada, 2007). PALS 2006 implemented a combination approach to defining chronic pain; in the filter section all participants were asked a series of seven pain related questions. These questions were then used to create the derived pain related variable, which takes into account the perspective set forth by Turk and Rudy (1988) that chronic pain is multidimensional. According to Turk and Melzack (2011), chronic pain is not just a sensory phenomenon and is now more commonly considered in a multidimensional model that incorporates sensory-physiological components with cognitive-evaluative and motivational-affects. Thus, the approach used in this study is a stronger approach to describe chronic pain as PALS 2006 provided better questions to determine the severity of chronic pain. The approach taken is consistent with that used by other researchers (eg. Mantyselka, et al., 2003).

As aforementioned, studies examining HRQoL have been conducted using two methods: a multiple item approach and a single item approach to measure HRQoL and each method is comprised of its own strengths and weaknesses (Fayers & Machin, 2000; Sloan et al., 2002). The use of a single item question, such as self-rated general health in a survey to measure HRQoL, is supported in the literature for several reasons; it allows the individuals

to provide a subjective assessment of their own health (Gill & Feinstein, 1994), which is found to be a very important predictor of mortality and a number of health outcomes even when controlled for the more objective measures of health (Mossey & Shapiro, 1982). Given the predictive value of single-item self-rated health, many studies used cross-sectional or longitudinal data for samples of the population to better understand what goes into individuals' ratings of their own health, which are found to be significantly predictive. There have also been population-based longitudinal studies in Canada (Shooshtari, Menec & Tate, 2007), and elsewhere, which have shown that individuals assess their overall health status as a multidimensional concept and base their ratings on a large number of factors including their physical health, mental health, social health, their social support resources, socio-economic situation, coping skills, and even changes in their health over time. It has also been established that the single item indicators are easier to administer on population-based surveys and less stressful for the participants (de Boer, et al., 2004; Fayers & Sprangers, 2002; Sloan et al., 2002). PALS 2006 measured HRQoL using a single question where respondents "were asked to rate their general health as, "Excellent", "Very good", "Good", "Fair", "Poor", to "Never/ Don't know/ Refusal". (Statistics Canada, 2007). As aforementioned, this variable was collapsed into "Positive HRQoL" which included "Excellent", "Very good", "Good" self-rated health and "Negative HRQoL" which included "Fair", and "Poor" self-rated health following a similar method used in prior research (e.g., Roychowdhury, et al., 2003; Jammoom, et al., 2008; Azarkeivan, et al., 2009).

A multiple item approach to measure HRQoL using the SF-36 among individuals with disability has raised concern. The SF-36 does not seem to be the most appropriate measure, especially its Physical Function domain for individuals with disability (Krahn et

al., 2009). The Physical Function domain in the SF-36 asks questions regarding agility and mobility, such as climbing a flight of stairs and bending/kneeling (Krahn, et al., 2009). An individual with a mobility or agility disability would probably respond “no” for many of the questions in this domain. The results would display a lower physical health status and not truly reflect the HRQoL of an individual who lives with a disability. For example, climbing a flight of stairs may never be an activity an individual with a mobility or agility disability would have to do if their environment had been accommodated for their needs. Therefore, in this study the single item self-rated health question was used as a valid measure of HRQoL. It is important to note that PALS 2006 provided cross-sectional data, and while appropriate to examine the relationship between chronic pain and HRQoL, causality cannot be examined.

One of the most recent conceptual frameworks to examine disability and health is the ICF. For the purpose of this study the ICF framework was used as the conceptual framework to examine not only health conditions but also HRQoL. The ICF is a model that does not only incorporate the perspective of the medical model of disability, but it also includes the social model of disability’s perspective of activity limitation and social participation. Therefore, the intent is that this model be used in multiple facets of research such as health, education, and disability policy (Cieza, et al., 2002). This research has modified the ICF conceptual framework to not only discuss an individual’s health but also to discuss how a health condition, but more specifically, chronic pain affects individuals’ HRQoL. Thus, in this study the modified ICF framework was used to examine how chronic pain (as a health condition), affects one’s HRQoL while controlling for the effects of body functions and structures (type of disability), activities (severity of disability), environmental (marital status

and social network), and personal factors (age, sex, total household income, education and onset of disability).

6.2 Chronic Pain and Associated Factors

Using the operational definitions discussed above, this research found that an estimated 68.63% of older Canadian adults (aged 55+) with disability reported chronic pain. This proportion is almost 2.5 times higher than that (27%) reported by older Canadian adults living in private households (Ramage-Morin, 2008), based on Statistics Canada's 1994/1995 through 2002/2003 National Population Health Survey and 2005 Canadian Community Health Survey.

This study found that with increasing age, older Canadian adults with disability were less likely to report severe and less severe chronic pain. More specifically, of Canadians with disability aged 55-64, an estimated 28% reported severe pain, which was decreased to 21% among those aged 65 years and older. These results are consistent with previous research by Brattberg, and colleagues (1989), who reported a decrease in reported pain after 65 years of age among the general older adult population. The differences in the reporting of pain could be due to changes in attitudes towards pain as individuals' age with the presence of pain. Many older adults may believe that pain is a natural part of the aging process and therefore, they could be more reluctant to report it, causing underreporting. Regardless of the decreasing prevalence, chronic pain is still a problem for this population as they age (Jakobsson, et al., 2003).

This study found that older Canadian females with disability reported chronic pain more than their male counterparts, which is consistent with findings of the general population studies (Bassols, et al., 1999; Grimby, et al., 1999; Sternbach, 1986; Crooks, et

al., 1984). These results could be due to sex differences in the manner in which both sexes discuss their pain or it is possible that there are true differences in the occurrence of pain between the sexes. It is suggested that males may have a decreased likelihood of reporting pain; even as they age they maintain stoicism caused by social pressures (Helme & Gibson, 1999). It is important that health care professionals be aware of these sex differences when caring for older adults with disability who may experience chronic pain but not express it.

The bivariate results revealed that there is a significant relationship between chronic pain and education. This finding is not consistent with some of the previous studies (e.g., Blyth, et al., 2001). Certainly, differences in the specific criteria used to define education could contribute to the differences between the present study and that of Blyth and colleagues (2001). For instance in their study, Blyth and colleagues (2001) found that individuals with a university or other post-secondary degree were more likely to report no chronic pain compared to those with less education. In this study, we found that those individuals who completed more than a high school diploma were more likely to report severe chronic pain than those who had lower levels of education. There might be several different explanations; those individuals with higher education may be more aware, more sensitive, and have more time to access resources. It could be hypothesized that those individuals with higher education were able to understand the mechanisms of chronic pain and the cognitive and behavioural responses more so than those with lower education, and thus reported more severe chronic pain. This finding suggests that when researching older adults with disability “well known sociodemographic characteristics of chronic pain”, such as education, are important factors to be considered.

In this study there was a significant association between chronic pain and the size of an individual's social network, with those having more friends being less likely to report chronic pain. More specifically, a lower prevalence of chronic pain was observed among older Canadian adults with a disability who had 20 or more friends relative to those without friends. This finding is consistent with previous research which suggests that social participation provides a sense of purpose and control, which in turn aids in one's ability to be flexible to live with disabilities such as chronic pain (eg. Diehl, 1998; Peat, et al., 2004). It is also possible that a larger social network acts as a buffer and may support coping with chronic pain. This study found that those older Canadian adults with disability who had smaller social networks (none, 1 to 2 friends and 3 to 5 friends) were significantly more likely to report severe and less severe chronic pain. These findings are similar with those of Peat, et al., (2004), who reported that among older adults (50 years and older, n=5215) the absence of a social network of close friends was significantly associated with increased risk of pain interference. Our findings supports the perspective that social support is beneficial as it provides individuals with positive experiences and socially rewarding roles, as well as, acting as a buffer against stressors (Cohen & Wills, 1985). It is important to note that as individuals' age, their social network decreases with the higher likelihood of being widowed and the absence of close friends and family.

Results from bivariate analysis also showed that older Canadian adults with agility and mobility disabilities had the highest proportion of reporting chronic pain (severe chronic pain 30.6% and 29.8% and less severe chronic pain 47.5% and 47.3% respectively). Jensen and colleagues (2005) found that among those individuals who reported having SCI, it was found that 79.6% of participants were experiencing or had experienced pain problems in the

previous 3 months. About 38% reported mild pain, 28% reported moderate pain and 33% reported severe pain. In another study, Budh and colleagues (2003) found that 63.7% of participants with SCI reported experiencing pain. There are many conditions that affect an individual's mobility and agility. Body movement often aggravates chronic pain and it is possible that an individual may consciously or unconsciously resort to strategies to avoid movement, which in actuality cause more pain and cause greater mobility and agility disabilities (Bortz, 1984). When an individual becomes disengaged their muscles start the process of deconditioning that puts the individual into an overall decline as they lose their independence, functional ability, and self-esteem (Bortz, 1984). Therefore, it is not surprising that chronic pain and mobility and agility disabilities co-occur. As well, some individuals who have disabilities such as fibromyalgia and osteoarthritis may have a difficult time distinguishing between the diagnosed health condition and the effect of pain (Mantyselka, et al., 2003).

This study found that a lower proportion of older Canadian adults with communication disability compared to no communication disability reported chronic pain. Thirty-five percent of older adults with communication disability reported severe chronic pain and 38.4% reported less severe chronic pain. In an earlier study, Odding and colleagues (2006) reported that approximately 80% of individuals with CP have a type of speech impairment and approximately 28% of individuals with CP reported experiencing chronic pain. Within the context of communication disability, those individuals with CP were examined as there are a large proportion of individuals with CP who not only experience communication disabilities but also chronic pain. When examining the prevalence of chronic pain among adults with CP, it was found that 18% of those younger than 30 years of age

reported chronic pain and this proportion was increased to 40% among adults up to 60 years of age (Jahnsen, Villien, Aamodt, Stanghelle, & Holm, 2004). However, it is important to note that this study focused on individuals 55 years of age and older and these age differences may account for the differences in the obtained results. As well, this study included a much broader terminology to describe communication disability, which may also account for the observed differences.

There was also a significant relationship between emotional disability and chronic pain among older Canadian adults with disability. More specifically, it was found that 50.3% of older Canadian adults with emotional disabilities reported severe chronic pain and 35.6% reported less severe chronic pain compared to 14% who reported emotional disability and reported no chronic pain. This result is consistent with previous research focusing on individuals with panic disorders (a type of emotional disability), which found that 38.3% of participants reported chronic pain (Kuch, Cox, Woszczyzna, Swunson, & Shulman, 1991). Results from the present study are also similar to those found by Arnow and colleagues (2006), who examined the relationship between major depressive disorders and chronic pain. These authors reported that 66% of those with major depressive disorders also reported having chronic pain. A review of the literature found that the prevalence of chronic pain among those who reported depression varied between 10%-100% (Romano & Turner, 1985). It could be postulated that the differences in reporting chronic pain among several types of emotional disabilities was due to the population and types of emotional disabilities which were included in the studies. This study applied a more general terminology to define emotional disability and it is believed that this allowed the research to incorporate various types of emotional disabilities. A possible explanation for the high levels of reported chronic

pain among older Canadian adults with emotional disability may be the fear-avoidance model of chronic pain (Lethem, Slade, Troup, & Bentley, 1983). According to this model individuals' fear of pain may lead to a variety of events such as avoidance of participation in activities that the individuals believe to cause them pain. Such avoidance behaviors may actually increase the occurrence of emotional disabilities such as depression or depressive symptoms. There is a cycle, which can take place as an individual becomes inactive to avoid pain and then becomes depressed and then becomes more inactive due to the depression and the pain, and the cycle therefore continues resulting in increased fear and avoidance. This may not be the only explanation as there may be others explaining the relationship between chronic pain and emotional disabilities. However, this is not the only explanation for the relationship between emotional disability and chronic pain. There is also the biopsychosocial perspective introduced by Engel (1977) and this aids in the understanding of emotional disabilities and pain (Gatchel, 2004). The biopsychosocial perspective views pain as the result of interaction between psychological, physiological and social factors. Therefore, when acute pain becomes chronic pain, the individual's premorbid or preexisting psychosocial characteristics can interact with the physical pathology of the chronic pain and affect the individual (Gatchel, 2004). Gatchel (2004), provide an example of this interaction. An individual develops chronic pain and loses his/her job and becomes seriously economically affected. This individual also has a premorbid problem of depression and depressive symptoms may be exacerbated during this time. It is important to highlight that there is not one particular preexisting "pain personaility" but rather to apply a more general approach; that there is a relationship among pain, psychosocial programs and personality (Gatchel, 2004). It must also be assumed that certain preexisting psychosocial characteristics

can differ from individual to individual and can be exacerbated by the stress put upon that individual to cope with chronic pain (Gatchel, 2004). It is possible that there are also other explanations of the relationship between chronic pain and emotional disabilities.

There was also a statistically significant relationship between chronic pain and learning disability. A review of the existing literature revealed that there were no studies available that examined the relationship between chronic pain and learning disabilities, making it difficult to explain the observed relationship. Therefore, to the best of our knowledge there is no theory. This is an area for further research.

In this study, 75% of individuals (37% reported severe chronic pain and 38.7% reported less severe chronic pain) with memory disability reported chronic pain. There are different conditions that could lead to memory disability such as traumatic brain injury and Alzheimer's disease. Lahz and Bryant (1996), studied this population (n=132) and found that among those with mild traumatic brain injury, 58% reported chronic pain and among those with moderate/severe traumatic brain injury, 52% reported chronic pain. One of the chronic conditions that initialize memory disability is Alzheimer's disease. Ramage-Morin (2008) reported the prevalence of chronic pain among older adults with Alzheimer's disease residing in institutions to be 36% for males and 42% for females. It is difficult to determine if individuals with various types of memory disabilities experience chronic pain in the same manner as cognitively intact adults. It has been postulated that if the somatosensory cortex is affected then the perception of pain may be altered (Farrell, Katz, & Helme, 1996).

However, it has been found that among individuals with memory disabilities such as Alzheimer's disease, emotions that are associated with pain could be changed due to the changes taking place in the brain (Farrell, Katz, & Helme, 1996). It can be postulated that

the differences between these studies could be due to the previously mentioned differences in brain characteristics as well as the characteristics of the study samples such as: type of disabilities, age, ratio of males to females, and the ability to recall chronic pain. PALS 2006 allowed the use of proxies to decrease the likelihood of the influence of the inability to recall the occurrence of chronic pain.

This study found that there was a significant relationship between seeing disabilities and chronic pain. About 32% of older Canadian adults with seeing disability reported severe chronic pain and 40.1% reported less severe chronic pain. Ramage-Morin (2008) found a similar prevalence rate of chronic pain among those with cataracts who lived in institutions; however, they used different definitions to evaluate chronic pain compared to the ones used in this study.

This study also found a statistically significant relationship between chronic pain and unknown types of disabilities. In this study unknown types of disability was defined by PALS 2006 as “if the respondent answered ‘YES’ to the general questions on activity limitations, but did not provide any ‘YES’ to the questions about type of disability that followed” (Statistics Canada, 2007b).

The results from this study found there was no statistically significant relationship between chronic pain and older Canadian adults with developmental and hearing disabilities. It can be postulated that individuals with developmental disabilities were under represented in PALS 2006. Moreover, if these individuals had a proxy response to PALS, it can be speculated that the proxy might not have been aware that they were unable to recognize chronic pain in older Canadian adults with developmental disabilities. Many older adults with developmental disability have difficulty communicating and might have sensory

impairments, or a combination of both which cause these individuals to experience and/or express chronic pain differently. Factors such as cognitive and sensory impairment, medical problems, and the presence of depression have been identified as possible contributing variables for the underreporting of chronic pain among older adults with developmental disabilities (Ferrell as cited in Reyes-Gibby, et al., 2002).

This study found a statistically significant relationship between severity of disability and chronic pain. About 52% of those with severe to very severe disability reported severe chronic pain and 36.6% reported less severe chronic pain compared to those who reported no chronic pain. Among those with mild to moderate severe disability, 3.3% reported severe chronic pain and 51.3% reported less severe chronic pain compared to those who reported no chronic pain.

This study found a statistically significant relationship between onset of disability and chronic pain. In this study, onset of disability was evaluated by a single question included in PALS 2006. Single variable questions have the potential to be problematic for individuals who have multiple disabilities; in addition, there is also the potential for recall bias. The results of the bivariate analysis of both chronic pain and HRQoL found that individuals, whose disability occurred between birth and age 18, reported less chronic pain as they could be better adjusted to their conditions than individuals who acquired their disabilities later in life. It is important to note that when examining onset of disability in relation to chronic pain, it is preferable to use longitudinal designs to collect information from the same individuals over several successive points in time. The longitudinal data obtained allows researchers to examine trends overtime. Moreover, it enables them to examine health transitions in relation to disability onset as individuals' age.

In this study we found that chronic pain is associated with negative HRQoL, which is consistent with previous research (eg. Katz, 2002; Reyes-Gibby, et al., 2002; Wang, et al., 1999). Katz (2002) provided a review of the literature regarding pain and QoL. This review found that nearly every type of pain, including chronic pain, has a damaging effect on an individual's QoL. For example, Katz (2002) found that when SF-36 was used to measure QoL, all eight subscores were greatly reduced when compared to the subscores of individuals' without pain. Reyes-Gibby et al. (2002) examined (n=5,807) older adults and found that pain was a significant predictor of fair to poor self-rated health. Wang et al. (1999) examined (n=216) adults diagnosed with metastatic cancer and used the SF-36 to measure HRQoL/functional health. They found that the severity of pain was associated with functional health; individuals with moderate or severe pain reported lower levels of mental and physical HRQoL than individuals with mild pain or no pain at all. Results of this study confirm results of prior studies that chronic pain negatively affects HRQoL. A number of other factors other than chronic pain were also found to be associated with negative HRQoL. Thus, in this study we examined the association between a wide range of sociodemographic factors, health-related factors, and HRQoL. Moreover, we conducted multivariate regression analysis to examine the relationship between chronic pain and HRQoL while controlling for the effects other significant factors.

6.3 HRQoL and Associated Factors

In this study, a statistically significant association was found between several characteristics and HRQoL among older Canadian adults with disability. More specifically, it was found that the HRQoL of older Canadians with disability is associated with their demographic and social characteristics (education, total household income, marital status

and social network) as well as disability-related characteristics (for example, type of disability and severity of disability).

HRQoL has been shown to vary by total household income, with those in lower total household income brackets being less likely to report positive HRQoL (Cott, et al., 1999; Shooshtari et al., 2007). The current study found that there are a similar percentage of individuals reporting positive and negative HRQoL between those who were married/living together and those who were not. This finding is similar to the findings by Cott and colleagues (1999). This study found that among those who were married/living together, a slightly higher percentage reported positive HRQoL. The size of social support network was statistically associated with HRQoL and the results displayed a pattern that as number of friends increases, the likelihood of reporting negative HRQoL decreases. However, this pattern does not apply for those individuals who reported having 1 to 2 friends. These individuals were more likely to report positive than negative HRQoL by only 0.2%. Also, there appeared to be a plateau effect; once an individual reported having more than 21 friends, the likelihood of reporting positive HRQoL was similar of those individuals with 6 to 10 friends.

The results of this study indicated that severity of disability was statistically associated with HRQoL, and those experiencing severe to very severe disability being more likely to report negative HRQoL compared to those who reported mild to moderate severity of disability.

Prior studies (eg. Poljicanin, et al., 2010; Bingefors & Isacson, 2004; Chia et al., 2007; Chia, et al., 2003; Davis et al., 2009; Aronld, et al., 2000), which examined the relationship of HRQoL and hearing disability found similar results. In this study only

hearing and developmental disabilities did not have a statistically significant relationship with HRQoL. It can be postulated that those with hearing disabilities feel as if they are part of the “Deaf” community. There are different meanings regarding the word “deaf”: small “d” refers to individuals with hearing impairments; big “D” refers to those who identify themselves with the Deaf culture and community. The Deaf culture indicates that it is comprised of more than just a shared language such as the American Sign Language (ASL). It includes special training and ways in which people conduct themselves to be part of the culture. It is also important to note that Padden and Humphries (2005) estimated that within Canada and the United States alone, there were between 100,000 and 300,000 individuals who use ASL as their first language. This makes the Deaf community larger than first language French-speaking individuals in both countries. It can also be postulated that those individuals who are part of the Deaf community feel a sense of belonging by having a buffer of external support that acts like a social network. The connection between hearing disability and the sense of belonging in the community is very unique. It can be suggested that the relationship between hearing disabilities and HRQoL is unique due to the extra external support and sense of belonging, which is provided through the sense of community that the Deaf culture provides.

As aforementioned, PALS 2006 may have under represented older Canadian adults with developmental disabilities. Many individuals with developmental disabilities have difficulty communicating and expressing how they are feeling about their health; as a result they may have been unable to answer PALS 2006 questions themselves. PALS 2006 allowed for proxy responding. If a proxy respondent answered for older adults with a developmental disability, the proxy may have inaccurately reported their HRQoL, as

HRQoL is subjective and personal. Individuals with developmental disabilities may have difficulty communicating how they are feeling which may also cause the proxy to respond incorrectly regarding how they would rate their HRQoL.

6.4 Chronic Pain is an Independent Determinant of HRQoL

Consistent with prior research, (eg. Closs, 2005; Reyes- Gibby et al., 2002; Wang et al., 1999) the results of this study indicated that chronic pain is significantly associated with negative HRQoL even after controlling for the effects of a large number of socio-demographic and disability related factors that are found to be associated with HRQoL. The strength of association between chronic pain and negative HRQoL increased with the increased severity of chronic pain, which displayed evidence of a dose-response relationship. Previous studies have displayed a similar dose-response relationship between chronic pain and HRQoL (Mantyselka, et al., 2003; Hunfeld, et al., 2001; Wang et al., 1999; Cleeland & Ryan, 1994; Becker, et al., 1997). This study confirms and provides additional evidence that chronic pain independently affects HRQoL among older adults with disability. The results, however, should be interpreted with caution, as the findings are based on cross-sectional data.

This research was intended to: 1) to describe the prevalence of chronic pain among older Canadian adults with disability, 2) to examine the relationship between chronic pain and HRQoL and 3) to assess if a dose response relationship exists between chronic pain and HRQoL. In this study we found that an estimated 68.63% (45.34% reported less severe chronic pain and 23.29% reported more severe chronic pain) of older Canadian adults with disability reported chronic pain. Only an estimated 31% of older Canadian adults with disability did not report chronic pain. Although a high proportion, it can be postulated that

this is an underestimation of the true prevalence of chronic pain among older Canadian adults since studies have found that older adults are more likely to experience chronic pain and less likely to report it than younger populations (Bernabei, et al., 1998; Melding, 1991). Older Canadian adults with disability who reported some degree of chronic pain were significantly more likely to report negative HRQoL. Those who reported more severe chronic pain had 3.34 times higher odds of reporting negative HRQoL than those who reported no chronic pain (95% CI= 2.28-5.15). It was also found that those who reported less severe chronic pain also had increased odds of reporting negative HRQoL which was significantly higher than the reference group (i.e., those with no chronic pain) [AOR=1.39; (95% CI= 1.02-1.88)].

Contrary to findings in previous studies, (Reyes-Gibby, et al., 2002; Cott, et al., 1999) age was not a significant determinate of negative HRQoL after controlling for the effects of chronic pain and all the other study factors. This finding could potentially be explained by the fact that as individuals' age they might unknowingly decrease their expectations of their health and due to this trend some individuals may rate their health to be more positive than it was in the past.

When controlled for the effects of all the other factors, sex was found to have a significant independent effect on HRQoL. More specifically, females had significantly decreased odds of reporting negative HRQoL when compared to the males (i.e., the reference group) [AOR=0.69; (95% CI= 0.55-0.88)]. This finding is similar to that reported by Cott and colleagues in 1999 [OR=0.60; (95% CI= 0.48-0.74)] and Zunzunegui and colleagues in 2004 [OR=0.75; (95% CI= 0.59-0.96)]. Female older adults have a more positive perception of their HRQoL than male older adults. This may suggest that females

have a more positive perspective of their health even though they are more likely to suffer from chronic conditions such as osteoarthritis and chronic pain. Women may also have a better coping mechanism and therefore do not as closely associate health conditions as negatively affecting their HRQoL compared to their male counterparts.

When controlling for all of the other study factors there was a significant association between total household income and HRQoL. Low total household income was significantly associated with negative HRQoL. Financial problems may have the potential to cause extra stress and affect one's HRQoL. Socioeconomic status may influence health by inadequate use or access to medical care, or other health and social services, which promote health and healthy behaviours (Williams & Collins, 1995). In a population-based study, Cott, et al. (1999), focused on self-rated health of Canadians 20 years and older with or without chronic health conditions or long-term disabilities. They found that lower income was associated with poorer health [OR=1.53; (95% CI= 1.25-1.87)]. This study found similar results. There were statistically significant increased odds of reporting negative HRQoL associated with low total household income (\$0-\$22,445 and \$22,446-\$42,415) and negative HRQoL.

The relationship between social support network and health among the older population has been examined extensively (eg. Wang, et al., 2005; Zunzuneguli, Kone, Johri, Beland, Wolfson, & Bergman, 2004). For example, Zunzunegui et al. (2004) examined the relationship between self-rated health and social networks among older Canadian adults in two French-speaking communities in Quebec. Zunzunegui et al. (2004), found that among those older Canadian adults with disabilities that affected their instrumental activities of daily living, those who had fewer friend based social networks had 1.06 increased odds of reporting poor self-rated health when compared to those who had

higher networks of friends [OR=1.06; (95% CI= 0.96-1.12)]. In this study there was a statistically significant relationship between negative HRQoL and social networks. More specifically, it was found that people with 11 to 20 friends had significantly lower odds [AOR=0.56; (95% CI=0.33-0.96)] of reporting negative HRQoL compared to those who had zero friends.

In this study the results displayed that older Canadian adults with mobility disabilities reported 2.62 times odds (95% CI=1.91-3.61) of reporting negative HRQoL when compared to those with no mobility disability. Moreover, after controlling for all other study factors there was a statistically significant [AOR=1.85; (95% CI=1.39-2.47)] association between agility disability and negative HRQoL. Hoeymans, Feskens, Kromhout, and van den Bos (1999), focused on the association between poor self rated health and chronic conditions and disabilities (back pain, cancer, coronary heart disease, diabetes mellitus, musculoskeletal complaints, respiratory symptoms, and stroke) in older male adults. They found that the odds of reporting poor self-rated health [OR=3.5; (95% CI=1.8-6.9)] were significantly increased when associated with a history of stroke among older males. In Hoeymans' et al. (1999) study, stroke was defined as a sudden onset of neurological paralyses that lasted longer than 24 hours. Neurological paralyses can include symptoms such as muscle weakness and poor coordination that have the ability to affect an individual's mobility and agility.

This study found that chronic pain was more strongly associated with negative HRQoL than types of disability or sex. Other studies (eg. Mantyselka, et al., 2003; Reyes-Gibby, et al., 2002) have also found a similar result that poor health is more strongly associated with chronic pain than chronic diseases and/or disabilities. Mantyselka and

associates (2003), found that among the general population aged 15 to 74 years with or without a chronic disease, those who experienced chronic pain several times a week had significantly greater odds of reporting poor health compared to those who reported no chronic pain [AOR= 2.62; (95% CI=1.76-3.90)]. In this study the association between negative HRQoL was statistically stronger, which could be due to the study participants' age or how chronic pain was defined. Mantyselka, et al. (2003), defined chronic pain as pain lasting for at least 3 months. At this point, the participants could identify the frequency of pain as: none, at most once a week, several times a week, and daily. Reyes-Gibby, et al. (2002), reported that among older adults living in the community with or without clinical health status (these variables were defined as the physical or mental dimensions of health), it was found that the odds of reporting poor self-rated health with the presence of chronic pain was 2.08 greater than those who did not report chronic pain. In this study the odds of reporting negative HRQoL when chronic pain was added was significantly higher than those without chronic pain. It can be hypothesized that this could be due to the definition used to define type of disability in this study compared to that used by Reyes-Gibby et al. (2002).

When controlling for the effects of all the study factors in the final multivariate model, except chronic pain, there was no statistically significant association between learning disability and HRQoL. The relationship remained non-significant after controlling for the effects of chronic pain as well [AOR=1.56; (95% CI=0.95-2.56); $p= 0.0759$]. These results indicate that HRQoL is not related to learning disability.

After controlling for all the other study variables, there was a statistically significant [AOR= 1.37; (95% CI=1.05-1.80)] association between seeing disability and negative HRQoL. Vision tends to decrease with age affecting an individual's visual acuity. Wang,

Mitchell, and Smith (2000) examined the relationship between reduced visual acuity and self-rated global health and found, that among older adults (80 years and younger) with reduction to their visual acuity, the odds of reporting low self-rated health was 2.1 (95% CI=1.5-2.9) times greater than those who did not report any reduction to their visual acuity (Wang et al., 2000). There was no significant relationship between reduction of visual acuity and the odds of reporting low self-rated health among those participants age 80 and older. Leskinen et al. (in press), examined determinates of self-rated health among Finnish war veterans. The results of this study displayed that visual impairment was related to a decline in self-rated health among males who reported having a disability [OR=1.66; (95% CI=1.00-2.76)]. This is significant as Leskinene and colleagues (in press) also controlled for pain in their multivariate regression. The differences in the results between the studies could be due to the older adult population being analyzed by Leskiene et al. (in press), which focused on veterans. Meanwhile, the analysis of Wang et al. (2000) focused on the general population, and not those with disabilities. It may be possible that older adults with impaired visual acuity may also have other health concerns that potentially affect their HRQoL.

Even though developmental disability was not found to be associated with HRQoL and chronic pain, it is important to highlight that these individuals', especially many older Canadian adults with developmental disabilities, may not be able to express their suffering from chronic pain. Therefore, this can lead to misconceptions of their needs and has the potential to affect their HRQoL. When examining chronic pain among individuals with developmental disabilities, it is imperative that the appropriate measurement and instruments are used. Individuals with developmental disabilities may have more difficulty to cognitively process that chronic pain is affecting their HRQoL, which appears to be an

inherent problem (Krahn, et al., 2009). These findings are significant as older adults are more likely to receive poorer pain treatment, especially those with cognitive impairments such as dementia (Morrison & Siu, 2000).

6.5 Mechanisms of Chronic Pain

There are a number of physiological and psychological mechanisms that may explain how individuals experience chronic pain. Brain structure can be altered when it is faced with any challenge that requires a specific function (May, 2007). It can then be postulated that the first chronification of pain comprises nociceptive input, and that neuroplasticity could occur in the modulatory areas of nociception (May, 2008).

6.5.1 Physiological Mechanisms of Chronic Pain

It has been found that there are changes in brain structure that cause enhanced pain and neural excitability in the CNS following a peripheral injury (May, 2007; Woolf & Salter, 2000). Bajaj, Madsen, and Arendt-Nielson (2003) have found that individuals with chronic pain presented characteristics of central hypersensitivity. As a result of tissue damage, an inflammatory response takes place that triggers the release of bradykinin, prostaglandins and other substances. The release of these substances, such as prostaglandin, increases the sensitivity of the pain receptors (Clancy & McVicar, 1992) and activates normally inactive nociceptors (Schmidt, et al., 1995). Following a long duration of nociceptive activity, it was found that A-beta fibers display a phenotypic switch and they start synthesizing receptors that are normally found in C-fibers and assume their characteristics (Neumann, Doubell, Leslie, & Woolf, 1996). A-beta fibers normally terminate deep in the dorsal horn; however, when the phenotypic switch takes place, this may create a termination in the superficial dorsal horn layers where C-fibers typically

terminate (Mannion & Woolf, 2000). It could be hypothesized that the body is responding to these hyperalgesia events and creating a protective mechanism. The importance of the anatomy and physiology associated with nociception is significant; however, it has been found that pain is not only caused by a response of nociception but that there are elements of the individuals' genetics, history, and psychological state which also must be taken into consideration (McCracken & Turk, 2002).

6.5.2 Psychological Mechanisms of Chronic Pain

The WHO found that individuals with persistent pain are four times more likely than their counterparts without pain to have depression or anxiety (Gureje, Von Korff, Simon, & Gater, 1998). The presence of chronic pain has the ability to be accompanied by a variety of other symptoms such as depression, physical dysfunction and social withdrawal (Rudy, et al., 1988). Romano and Turner (1985) displayed there is a close relationship between pain and depression. Several studies have also found a similar trend that clinical depression and depressive symptoms have been related to both chronic pain (Parmelee, Katz, & Lawton, 1991) and poor self-rated health (Cott, et al., 1999; Reyes-Gibby, et al., 2002; Leskinen et al., in press). As of yet, it is unknown if depression is a precursor or consequence of chronic pain (Mantyselka, et al., 2003; Dworkin & Gitlin, 1991).

The pain experience may be increased by the presence of pain related fear and anxiety (Crombez, et al., 1999). Individuals with anxiety disorders have been found to report chronic pain more than those with depression (Von Knorring, 1975). In 1987, Philips put forth the idea that individuals with chronic pain may avoid stimuli that are associated with their pain symptoms. Therefore, an individual may disengage in activities because there is anticipation that by participating there will be an increase of pain. These behaviours are

explained by the fear-avoidance model (Lethem, et al., 1983). Over a long period of time, fear-avoidance behaviours can have a negative effect on social and physical activities resulting in loss of self-esteem, mobility, and muscle strength which can result in ‘disuse syndrome’ (Bortz, 1984). Chronic pain is found to be associated with psychological disabilities/distress as well as significantly creating activity limitations (Gureje, & et al., 1998) that are found to be associated with negative HRQoL.

6.6 Potential Limitations

The current research must be considered in light of several limitations. The primary limitation of this study was the cross-sectional nature of the data used. The cross-sectional study method is comprised of observations of a sample of the population that are made at one single point in time. The inherent problem of using cross-sectional surveys is that conclusions are drawn from observations made at one single point in time and do not allow the researcher to understand the process over time (which is what a longitudinal study allows for). Future studies with longitudinal designs are needed to explore the temporal directions of the associations between the study variables, and in particular chronic pain and HRQoL, which was the focus of this study. Although Statistics Canada put into place many steps to warrant reliable and valid data, there are still many limitations in national health and social surveys including PALS 2006. For example, data from these surveys are susceptible to recall biases and respondents may provide answers which are socially acceptable, inaccurate, and/or influenced by subjectivity. In addition, there may be different responses provided if an individual is answering these questions alone versus having one or more individuals in the same room with them while taking part in the survey. Another challenge is that responses may be influenced by an individuals’ inclination in reporting their disabilities

and their own perception of them (Statistics Canada, 2007b). In today's society, this may be unavoidable due to the challenges surrounding the collection of data on individuals with disabilities and those disabilities upon which society has conferred a stigma. However, a comparison between the 2001 and 2006 PALS indicated that there was a great increase in the number of individuals who reported mild disability and an even greater increase among those who reported severe disability (Statistics Canada, 2007b). This increase in reporting of disabilities in Canada displays that Canadians are starting to become more accepting of those individuals with disabilities and that those with disabilities are feeling more comfortable acknowledging and reporting their disability.

A secondary limitation that should be noted is that although PALS includes persons with all types of disability, individuals with developmental and memory disability may be under represented in this survey as the sampling framework did not include those individuals who reside in institutions such as long-term care facilities (Statistics Canada, 2003). Another potential source of bias is proxy responding. PALS allowed for proxy responding if a respondent was absent for the duration of the survey, was unable to speak English or French, or was unable to participate due to a mental or physical disability (Statistics Canada, 2007). The proxy respondent was required to be a caregiver, child, parent or spouse and was able to respond on their behalf based on the understanding that the proxy respondent was the most knowledgeable about the individual's challenges and difficulties faced due to their activity and participation limitations (Statistics Canada, 2007). Proxy responses were common in the 2006 PALS adult survey, especially among those participants 75 years of age and older (Statistics Canada, 2007). There was no information on proxy responding in the PALS 2006 master data file. As a result, the type of relationship the proxy respondents had with the

individuals on whose behalf they answered the survey is not known. However, Statistics Canada reported the overall proxy rate for PALS 2006 among individuals aged 15 years and older was 12.1% (Statistics Canada, 2007). Since only data for persons with disability aged 55+ were used, in some instances, response categories for study variables had to be collapsed due to small cell sizes, creating limitations for data analysis and reporting.

The outcome measure HRQoL was a single question based on an individual's self-perception and was not a combination of subjective and objective measures, which is ideal to measure HRQoL. It is also possible that an individual may be reporting that their HRQoL is significantly lower than it actually is; this may be the result of the effects of social stigma, which are often found to be present (Poweel & Lowenstein, 1996).

To allow for identification of the type of disability, which is associated with activity limitations, PALS developed questions based on the WHO's framework of disability provided by the ICF (Statistics Canada, 2007). Using this framework, disability is described as the relationship between the body structures and functions, daily activities, social participation, and the recognition of the role of environmental factors. By using this definition the ICF provides a multidimensional classification of disability, which incorporates both the medical and social model of disability (Statistics Canada, 2007).

However, Oliver (1990) provides a method to determine the true origin of disability questions. When Oliver's method was applied to PALS 2006, the questions did not encompass a balance between the social model of disability and medical model of disability. PALS use of the WHO's ICF framework suggests that the questions represent a social model of disability perspective; however, following an analysis of the questions used in PALS 2006 and the definition of specific types of disability, the use of the social model of

disability in the survey is questionable. It can be suggested that in order for PALS 2006 to have included the social model of disability perspective in their questionnaire, it would have been necessary to have a greater focus on the environmental factors as it is those barriers which prevent participation and less of a focus on the impairment. Thus, this would create a balance between both the medical model of disability and the social model of disability. The use of questions based on the medical model of disability is vivid in the PALS 2006; an example is a filtering question, which classifies participants into one or more types of disability. PALS 2006 also examined the severity of an individual's disability based on the degree of activity limitations one experienced ranging from "Very severe", "Severe", "Moderate", and "Mild".

6.8 Practice and Policy Implications of the Study Findings

The results of this study displayed that an estimated 45.34% of older Canadian adults with disability reported less severe chronic pain and an estimated 23.29% reported more severe chronic pain. Thus, chronic pain of some level is highly prevalent among older Canadians with disability. These findings suggest that there is a need for health care professionals to frequently assess their older adult clients with disability for the presence of pain. It is relatively common among the older adult population that pain is under-treated (Ross & Cook, 1998). Self-reporting of pain is the most commonly used and reliable measure of pain intensity (Turk & Melzack, 2011). Other psychometric evaluations of pain intensity scales exist such as: the visual analogue scale (VAS), the verbal descriptor scale (VDS), and the numeric rating scales (NRS) (Herr & Garand, 2001). These tools/scales were developed and validated for use among the younger adult population. Therefore, it is not appropriate to assume that they are also valid for older adults, particularly those with

cognitive difficulties and those who are frail (Gauthier & Gagliese, 2011). As well, these scales are not always appropriate to measure pain among older adults with disability as an individual must have the ability to read, hear, and understand directions in order to complete these tools used to assess pain (Herr & Garand, 2001). In addition, when these types of tools are used, they only measure pain intensity, which fails to incorporate the multidimensional nature of pain (Turk & Melzack, 2011; Turk & Rudy, 1988). Therefore, using one dimension of pain, such as intensity, it does not take into account several other dimensions related to pain such as severity and/or prognostic variables (Von Korff, 1992).

Implementing a uni-dimensional pain measurement tool does not fully measure pain; a multidimensional pain measurement tool provides an instrument that matches the multidimensional nature of pain. Self-reporting of pain is often done verbally; however, non-verbal reports must also be considered. PALS 2006 incorporated a type of non-verbal report by incorporating proxy respondents, which is very feasible for a national survey. Although the use of the Facial Action Coding System (FACS) (Ekman & Friesen, 1978) and the Pain Behaviour Measurement (PBM) (Keefe & Block, 1982) are too time-consuming to implement in a clinical setting or to be implemented on a national survey, they remain an effective tool to measure pain among adults with cognitive impairment (Hadjistavropoulos, et al., 2011). Further research is necessary to develop a pain assessment tool that is appropriate for use among the older adult population yet short enough to be included in a national health survey such as PALS.

Specific attention to healthcare policy is necessary when providing care to older adults with disability. In particular, older adults with agility disability, learning disability,

mobility disability and seeing disability were more likely to report negative HRQoL compared with positive HRQoL even when controlling for all possible covariates.

This study found that chronic pain does have a negative impact on the HRQoL of the individual who is being affected by this pain. When healthcare services do not focus on the implementation of effective prevention and treatment strategies for chronic pain they are not doing their due diligence to provide proper healthcare services to this population. The lack of proper healthcare focus also imposes an unnecessary burden on individuals living with chronic pain and displays an incompetent professional expertise regarding chronic pain.

This research puts forth the idea that due to the large percentage of older adults with disability experiencing chronic pain, pain should be routinely assessed in medical practice at the same rate as heart rate and blood pressure. The study by Breivik, Collett, Vantafridda, Cohen, and Gallacher, (2006) reported that approximately one-fifth of individuals said their medical professional had never asked them about pain. Individuals with disability have expressed that they experience chronic pain but these expressions are often pushed to the way side and some medical professionals either avoid the individual in pain or blame that individual for being in pain (Wendell, 1996). This lack of medical care needs to change. The need for this change ensures that individuals with chronic pain are receiving proper care and treatment, in a timely manner, to prevent the occurrence of the dose-response relationship, which this research confirmed occurs between negative HRQoL and chronic pain. It is also significant to mention that these concerns are the same among the general population and that one-fifth of individuals felt that their medical professionals did not view pain as a problem and over 40% reported that their medical professional said they would rather treat their illness than their pain (Breivik, et al., 2006). Medical professionals need to pay more

attention, listen to the needs of their patients, implement the correct assessment tools, and execute pain management/pain treatment strategies (Mantyselka, et al., 2003). This is especially significant for the older adult population whose pain is at a greater risk for poor pain treatment (Morrison & Siu, 2000). Improved HRQoL can be achieved by the care provided to older adults with disabilities. An example of this is the use of sufficient pain assessment and pain relief.

It is important for medical professionals to treat and manage the underlying condition, as well as, to address and develop a strategy to tackle the presence of chronic pain (Breivik, et al., 2006). At the community or social level, it is important that health-promotion strategies are used in pain management as well as pain prevention (Mantyselka, et al., 2003). The Precede-Proceed Model of health program planning (Green & Kreuter, 1991) has been widely used to improve health promotion behaviours in the community. Following the Preceded model, the first step to developing a health promotion program is identifying health problems through a three step process: epidemiological diagnosis, behavioural diagnosis and educational diagnosis (Green & Kreiter, 1991). These are significant as individuals have the ability to change their comparison and frame of reference over time with different healthcare treatments and experiences. Therefore, HRQoL has the ability to fluctuate overtime (Fayers, Langston, & Robertson, 2007). An example of a health-promotion strategy is providing knowledge and education to older adults as well as the caregiver regarding chronic pain relief. If those with chronic pain disability are provided with adequate medical care, then it is possible that chronic pain will display less of a dose-response relationship between chronic pain and negative HRQoL.

The findings of this research displays that chronic pain is a significant health problem among older Canadian adults with disability. Serious consideration needs to be put towards chronic pain by medical professionals as well as healthcare policy makers.

6.9 Research Implications of the Study Findings

The current research findings suggest that the prevalence of chronic pain among older adults with disability is significantly higher than the general population; therefore, it is important to assess the impact of chronic pain on an individual's HRQoL with a broader range of information. Further research should aim to examine if HRQoL is affected by the number of co-occurring disabilities that individuals acquire as they age. In addition, sex differences in HRQoL have been found to be an important area of research, as there seems to be a sex-effect on both chronic pain and HRQoL. Finally, further research should examine the long-term effects of chronic pain on HRQoL on a continuous basis using longitudinal data.

6.10 Summary and Conclusions

In summary, the current research represents the first nationally representative examination of HRQoL and chronic pain in older Canadian adults with disability. The results play a significant role in the understanding of the presentation, diagnosis, and treatment of chronic pain among older adults with a broad range of disabilities. Importantly, the results suggest that living with chronic pain along with another disability is more likely to result in negative HRQoL. This study highlights the importance of proper pain assessment and management for older Canadian adults. Here in Canada, the primary health care providers are usually general practitioners who should start dialogue with their patients especially about pain and pain related issues. These findings suggest greater opportunities

for practicing healthcare/medical professionals who work with older adults to intervene in an attempt to decrease chronic pain and thus promote higher quality of life for older Canadians. For example, the knowledge of co-occurring chronic pain and disabilities in older adults may increase the likelihood of careful pain assessment, and in turn, lead to prevention and treatment to improve the HRQoL. Older Canadians with disability, both males and females and the more socially disadvantaged, should be the target of pain assessment and management programs.

In Canada the collection of national level data on individuals with disabilities has been discounted as of 2011 Census. National level data of longitudinal nature is needed to examine trends overtime and to inform policy and practice. This data is particularly important with the aging of the baby bomber population, as it has been displayed that as individuals age there is a greater probability of disability occurring. Without such data as PALS it is not known how these individuals are being affected and it is unknown how to better provide care and/or disability support programs as well as funding to create or maintain such care or programs.

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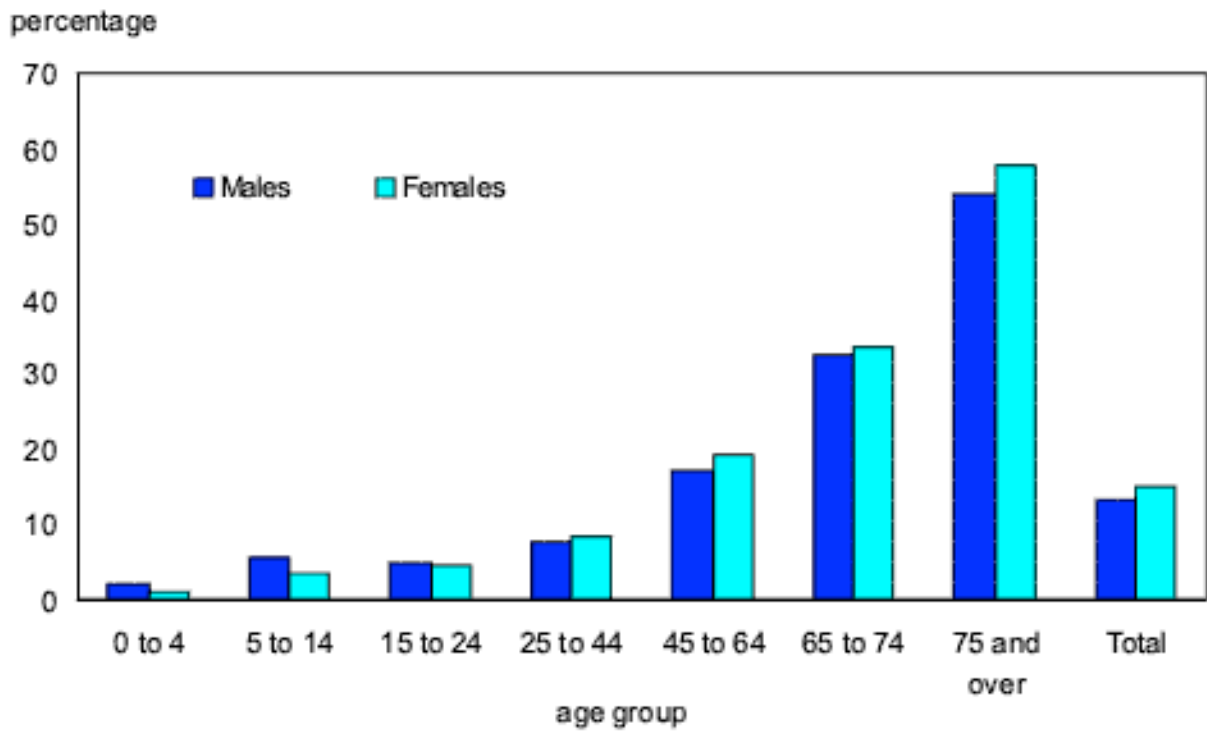
Appendix A: Concepts of Impairment, Disability and Handicap Used in the ICDH (WHO, 1980).

Term	ICIDH Definition
Impairment	Any loss, or abnormality, of psychological, physiological or anatomical structures or functions.
Disability	Any limitation or loss (due to an impairment) of ability to perform an activity or variations in the way considered normal for a human being.
Handicap	Is a disadvantage experienced by a particular individual, as a result of an impairment or a disability that limits or prevents the opportunity to fill a “normal” role in relation to age, gender and sociocultural factors for that particular individual.

Appendix B: Concepts of Body Functions, Body Structure, Activities and Participation, and Environmental Factors, used in the ICF (WHO, 2002b).

Term	ICF Definition
Body Functions	Are the psychological and physiological functions of the body system.
Body Structures	Body structures are anatomical parts of the body such as organs, limbs and their components.
Activities and Participation	Activity is the execution of a task or action by an individual. Participation is involvement in a life situation.
Environmental Factors	Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.
Personal Factors	Personal factors may include: age, education, gender, social background and any other factors which may affect the experience of disability.

Appendix C: Disability rate by age and sex in Canada, 2006
Source PALS, 2006 (Statistics Canada, 2007b).



Appendix G: List of Variables

Original Variable	Recoded Variable	Labels	Values
AGE	AGER	Age	Categorical 1) 55 to 64 2) 65 to 74 3) 75+
HCDD	Education	Education	Categorical 1) Less than High school 2) High School 3) More than high school
MARST	MARSTR	Marital Status	Binary 1) Alone 2) Together
HHINC	HHINCR	Total Household Income	Categorical 1) \$0 to \$22445 2) \$22446 to \$42415 3) \$42416 to \$72040 4) \$72041+
zz_sex_imputed	SEXR	Sex	Binary 1) Female 2) Male
Deg_Pain	Pain3	Chronic Pain	Categorical 1) No Disability 2) Less Severe 3) More Severe
AALR_Q01	AALR_Q)01R2	HRQoL	Binary 1) Positive HRQoL 2) Negative HRQoL And 0) Positive HRQoL 1) Negative HRQoL
DGREE	DEG_Sev3	Degree of Severity	Binary 1) Mild to Moderate 2) Severe to Very Severe

AUNK_D_A_LIM	Other_Dis	Other Disability	Binary 1) Yes, Other Disability 2) No
AAFT_D_A_LIM	Agil	Agility Disability	Binary 1) Yes, Agility Disability 2) No
ADFT_D_A_LIM	Develop	Developmental Disability	Binary 1) Yes, Developmental Disability 2) No
AHFT_D_A_LIM	Hear	Hearing Disability	Binary 1) Yes, Hearing Disability 2) No
ASFT_D_A_LIM	See	Seeing Disability	Binary 1) Yes, Seeing Disability 2) No
AMOF_D_A_LIM	Mob	Mobility Disability	Binary 1) Yes, Mobility Disability 2) No
ALFT_D_A_LIM	Learn	Learning Disability	Binary 1) Yes, Learning Disability 2) No
AMFT_D_A_LIM	Mem	Memory Disability	Binary 1) Yes, Memory Disability 2) No
AEFT_D_A_LIM	Emot	Emotional (Psychological) Disability	Binary 1) Yes Emotional Disability 2) No
ACFT_D_A_LIM	Comm	Communication (Speech)	Binary 1) Yes, Communication Disability 2) No


LIMDUR	Onset of Disability	oonsetSet	Categorical 1) 0-18Yr 2) 19-54 3) 55-64 4) 64-74 5) 75+
ASC_Q09	Social network None Family	Friends	Categorical 1) None 2) 1 or 2 3) 3 to 5 4) 6 to 10 5) 11 to 20 6) 21+

Appendix E: Definitions of each of the ten types of disability (Statistics Canada, 2007b).

Type of Disability	PALS Definition
Agility	Difficulty bending, dressing and undressing oneself, getting into or out of bed, cutting own toenails, using fingers to grasp or handling objects, reaching in any direction (for example, above one's head) or cutting own food.
Developmental	Cognitive limitations due to an intellectual disability or developmental disorder such as Down's syndrome, autism or an intellectual disability caused by a lack of oxygen at birth.
Hearing	Difficulty hearing what is being said in a conversation with one other person, in a conversation with three or more persons, or in a telephone conversation.
Learning	Difficulty learning because of a condition, such as attention problems, hyperactivity or dyslexia, whether or not the condition was diagnosed by a teacher, doctor or other health professional.
Memory	Limited in the amount or kind of activities that one can do due to frequent periods of confusion or difficulty remembering things. These difficulties may be associated with Alzheimer's disease, brain injuries or other similar conditions.
Mobility	Difficulty walking half a kilometer or up and down a flight of stairs, about 12 steps without resting, moving from one room to another, carrying an object of 5 kg (10 pounds) for 10 meters (30 feet) or standing for long periods.
Pain	Limited in the amount or kind of activities that one can do because of a long-term pain that is constant or reoccurs from time to time (for example, recurrent back pain).
Psychological	Limited in the amount or kind of activities that one can do due to the presence of an emotional, psychological or psychiatric condition, such as phobias, depression, schizophrenia, drinking or drug problems.
Seeing	Difficulty seeing ordinary newsprint or clearly seeing someone's face from 4 meters away (12 feet).
Speech	Difficulty speaking and/or being understood.

Type of Disability	PALS Definition
Other	The type of disability is 'other' if the respondent answered YES to the general questions on activity limitations, but did not provide any YES to the questions about type of disability that followed.

Appendix F: Ethics Approval.



UNIVERSITY OF MANITOBA | Office of the Vice-President
(Research and International)
Research Ethics and Compliance

APPROVAL CERTIFICATE

February 2, 2012

Human Ethics
208 - 194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Fax 204-269-7173

TO: Kristina Alexandra Zawaly (Advisor S. Shooshtari)
Principal Investigator

FROM: Wayne Taylor, Chair
Joint-Faculty Research Ethics Board (JFREB)

Re: Protocol #J2012:020
"Examining the Relationship between Chronic Pain and Health Related
Quality of Life among Older Canadian Adults with Disability"

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to the Office of Research Services, fax 261-0325 - please include the name of the funding agency and your UM Project number. This must be faxed before your account can be accessed.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba Ethics of Research Involving Humans.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

umanitoba.ca/research/orec